

POETRY “FOUND” IN ILLNESS NARRATIVE: A FEMINIST APPROACH TO  
PATIENTS’ WAYS OF KNOWING AND THE CONCEPT OF  
RELATIONAL AUTONOMY

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## ABSTRACT

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### POETRY “FOUND” IN ILLNESS NARRATIVE: A FEMINIST APPROACH TO PATIENTS’ WAYS OF KNOWING AND THE CONCEPT OF RELATIONAL AUTONOMY

This project contributes to the improvement of the healing encounter between physician and patient and broadens the scope of medical ethics via application of a methodology that creatively communicates patient experience. Contemporary medical training and socialization can create emotional distance between patients and physicians, which has both positive and negative effects. A physician’s “detached concern” often renders patients’ ways of knowing irrelevant to their care. This has a negative effect on patient autonomy, trust, and the healing encounter in general. Herwaldt (2008) developed a pedagogical tool of distilling patient interviews in narrative form into “found poems,” in which the patient experience is expressed in verse; Herwaldt contends that the resulting poems hold the possibility of cultivating empathy in medical practitioners. My research extends Herwaldt’s work with a new set of ten patients currently in cancer treatment, translating their stories of illness into verse. The resulting poems have the potential to empower patients by legitimizing their narrative or experiential ways of knowing as complementary to physician perspectives and approaches to treatment. Clinical and feminist ethics are similar in their attention to case context, empathy, and legitimacy of narrative. However, there are aspects of feminist ethical theory that are not thoroughly delineated in clinical ethics—specifically, attention to power imbalances in medical structures and variations in ethical perspectives. When the poems are examined using a feminist bioethical framework, patients are empowered by expanding both the idea of justice and the principlist definition of autonomy to include the feminist conception of *relational* autonomy.

Peg Brand, PhD, Committee Chair

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## 1.0 INTRODUCTION

Personal stories of illness—which can take the form of texts (poetry, prose) and images (visual media)—are more important than ever to doctors and other medical professionals in becoming more effective and respectful healers. The fact that these narratives exist in many forms likely conveys the human need to share stories in the name of healing. Many forces restrict physicians’ abilities to reflect on their clinical experiences and relationships. Without ample reflection, medical practice is unable to grow and become more humane. Contemporary medical training and socialization can create emotional distance between patients and physicians, which has both positive and negative effects. Negatively, a physician’s “detached concern” can render patients’ narrative or experiential ways of knowing irrelevant to their care. This has a negative effect on trust between patient and doctor, and the healing encounter in general. The current marketplace of healthcare speeds up the encounter between patient and doctor, preventing a deeper connection that would facilitate healing. The pervasive use of computers has replaced handwritten notes in patients’ charts, possibly to the detriment of physicians’ processing and intellectual and emotional understanding. The innovations of medical technology which have been beneficial to a great number of patients further remove the doctors from the people’s suffering and remove the human element of the illness experience. Paradoxically, the work of physicians is “centered on telling stories and on hearing stories, and by choosing one kind of story over another, we can transform our practice of medicine” (Charon 1986, 10). The narrative medicine movement seeks to bring practitioners back, closer to the stories of illness, to more humanely and effectively bring about healing.

### *Narrative and Ethics*

Narrative has been variously described as a “fundamental way of organizing human experience and as a tool for constructing models of reality” (Pullman et al. 2005, 280). Narrative medicine, as defined by Charon (2001) is medicine practiced with the ability to “recognize, interpret, and be moved to action by the predicaments of others” (83). Both sickness and healing can be conceived as narrative acts, and Hunter (1991) has pointed out that even medical knowledge itself is narrative-based. Narrative techniques

utilized in medical practice can both assist the sufferer in enduring illness, and confer on clinicians a new kind of understanding and ability for reflection, as narrative practices encourage doctors to reflect on the experiences of their patients (Charon 2001). This reflection seems to be the precursor to empathy; if physician socialization leads to potentially cold and detached attitudes on the part of new practicing doctors, then narrative medicine is presented as a potential repair for this predicament. With development of skills in empathy and reflection, could more humanism and professionalism follow? Coulehan (2006a) notes that the pervasive belief in medicine—and traditional ethics—that emotional response weakens us is by no means evidence-based. Much of ethical theory is just that: theory. It often invokes rules and principles that are designed to work from the top down. Using narrative to derive ethical conclusions, or narrative ethics, brings a closer lens to the stories behind ethical dilemmas. Rather than theory alone, a narrative bioethics is a bioethics that focuses on key moments of the medical encounter—instead of overarching theories and rules to be applied to ethical decisions, a narrative ethics can closely examine the moment of diagnosis or interaction with a physician. It is a bioethics grounded in the grassroots.

The institution of medicine, as it stands, promotes a specific kind of truth—scientific truth that can only be proven with chemical tests or imaging studies, decipherable only by those who have been trained to do so. The power is in the hands of those with knowledge, and this can lead to decision-making and interventions that sometimes override patient autonomy. In the case of medical uncertainty or disagreement between practitioners, information can be distorted by the time it reaches the patient. Disclosure of medical error is infinitely complicated by the litigious culture of the United States. Even if medicine promotes individual patient autonomy and completely informed consent, as long as the knowledge is disseminated by one party (the physician) and received by another (the patient) in the medical encounter, this autonomy based on informed consent is incomplete. As long as the power differential favors the physician role, patients are at a disadvantage. “Currently, medical ethics is overwhelmingly physician ethics” (Warren 1989, 82-83). Bruner (1985) makes a distinction between *paradigmatic* and *narrative* ways of knowing. He defines paradigmatic as logico-scientific, requiring formal verification and empirical proof, and it is this way of knowing



which holds authority in medicine. The narrative way of knowing involves stories of human interaction, which is the way of knowing reflected in patient experience and narratives. Shifting power to the patient calls for more listening.

I adopt Bruner's term *narrative*, as it is able to get much closer to what I have found in my patient narratives and what I seek to legitimize. However, I seek to build upon and go beyond Bruner's definition, as it stands to gain from feminist theory. A narrative way of knowing combines aspects of intuition and experience. It is also subjective. Belenky et al (1986) define subjective knowledge as what can be gleaned from the "inner voice," or the intuition; they find that subjectivist knowers "distrust logic, analysis, abstraction" (71). For subjective knowers, truth is an intuitive reaction, experienced and felt. Subjective truth is unique to each individual, an "accident of personal history and experience" (69). Beyond subjective knowing is *connected* knowing, which "builds on the subjectivists' conviction that the most trustworthy knowledge comes from personal experience rather than the pronouncements of authorities" (112-113). *Constructed* knowledge integrates intuitive knowledge with knowledge learned from others through listening. For Belenky et al (1986), *listening* is a way of knowing. There are elements of all of these ways of knowing—intuitive, experiential, subjective, connected, constructed, listened and heard—implicit in my use of Bruner's *narrative* term throughout.

### *Poetry, Medicine and Patient Listening*

The concentration of medical education on hard science and technology has perpetuated a separation between the life of the individual and his or her own physical body. Herwaldt (2008) developed a pedagogical tool of distilling patient interviews in narrative form into "found poems," in which the patient experience is expressed in verse; Herwaldt contends that the resulting poems hold the possibility of cultivating empathy in medical practitioners. Herwaldt interviewed patients about their illness experiences, transcribed the interviews, removed redundant words and added line breaks, forming the result into a poem on the page. She interviewed those who had written about their illness experiences and published their narratives because she felt that it was these patients who had already been able to reflect deeply on their experiences and therefore might have had

deeper insights to share. My research extends Herwaldt's work with a new set of ten patients currently in cancer treatment, who have not yet written down or otherwise formally shared their experiences, translating their stories of illness into verse. My project contributes to the improvement of the healing encounter between physician and patient and broadens the scope of medical ethics via application of a methodology that creatively communicates patient experience. Poetry and medicine share several relevant parallels, and this facilitates the expression of patient experiential data in the form of verse. The poems that I have "found" have the potential to empower patients: first, by legitimizing their narrative ways of knowing as complementary to physician perspectives and approaches to treatment, and second, by refining the dominant bioethical ideal of autonomy.

Herwaldt finds that her found poetry has the potential for cultivating listening skills in physicians and medical students, promoting empathy and more rewarding patient-physician relationships. When students, physicians, and laypeople are exposed to the poems derived from patient experience, they must pay close attention to perspectives that are not often given voice in the medical encounter. The perspectives of patients on their own illness experience and their own bodies can be discounted, becoming secondary to biomedical truth—test results, for example. Given consideration in a unique way in my research results, these patients' perspectives illuminate feminist bioethical principles in a new and creative way. These feminist principles can influence clinical bioethics; a feminist-inspired clinical ethics more effectively addresses systemic injustices in the medical establishment. It would pay more attention to justice and equality toward women and other marginalized identities along the lines of race, class, ethnicity, religion, and sexual orientation. The feminist ethical framework offers a constructive critique of bioethical principlism and autonomy specifically, along with a revaluing of emotion in ethical deliberation that would support the practice of clinical ethics. If applied, feminist theories have a great deal to offer medical ethics as far as refining concepts of autonomy—toward a *relational* conception— and justice.

Herwaldt's choice of poetry as a medium is more than an arbitrary or aesthetic choice. Poetry requires empathy, and seeing connections, much like medical practice itself. Coulehan (2006a) writes that in medical practice, there is a tension between

detachment and connection, objectivity and subjectivity, and steadiness and tenderness. Likewise, poetry creates great tension in its language and structure. Physicians, in their practice of medicine, have “unusually broad and deep access to human suffering” (2006b, xii) Both medicine and poetry are a study in contrasts: life and death, light and darkness, joy and suffering. Coulehan (2006a) asserts that the tensions in medicine can generate creative energy on the part of both physician and caregiver. Indeed, “there is a terrible poetry to suffering” (Coles 1989, 100). Coulehan (1998) writes that medicine and poetry draw from the same deep well, presumably that of human emotion, relationships, and experience. At the center of medicine is the “poetic act of *being with*, simply standing in the presence of suffering,” and like poetry, “medicine cannot be stripped of metaphor, image, symbol, meaning, and interpretation” (xvi). There is a great deal of grey area in medicine—with medical uncertainty, patients must often reside among absolutes—cure and failure, positive and negative, lab values present and absent. It is often uncomfortable for both patients and practitioners to exist in the uncertainty of the gray area. If medicine is expectation, training, and discipline, then how can one account for uncertainty, intuition, and luck? Poetry often seeks to put words to those grays, to the uncertainty and the ambiguities encountered as part of the human condition. Poetry allows for finding comfort in the gray area of human existence, and order in chaos. Indeed, “the imaginative thinking expressed in certain kinds of stories or poems occupies this shadowy area between particulars and generalities, rules and exceptions” (Shapiro 1993, 10). Poetry also has parallels with ethics. Shapiro (1993) writes that practical ethical reasoning must go beyond the “mechanical application of a set of rules; like “poetic reasoning’ it entails attention to particulars, a readiness for the surprising, and some capacity to improvise” (9). He offers poetry as a way to mediate our ethical judgment, and recommends that we cultivate this ethical imagination using poetry

Embedded in my poetic research results, we have narrative and narrative ethics, in which ethical principles can be derived from life stories; both medical ethics and feminist ethics incorporate narrative to differing degrees in getting to their ethical conclusions. For Johnson (1993), “unless we can put ourselves in the place of another, unless we can enlarge our own perspective through an imaginative encounter with the experience of others, unless we can let our own values and ideals be called into question from various

points of view, we cannot be morally sensitive” (199). My project gets to both the principlist goal of honoring patient autonomy—albeit a relational, feminist idea of autonomy—and to the aim of feminist ethics of identifying and working to end “oppression,” wherever it can be perceived. My results contribute to generalizable knowledge of the experience of patients who have been previously voiceless. Creating and interpreting poetry requires close listening, and close listening works toward promoting more empathic caregivers. Spiro (1993) writes that “the ear is as important as the eye in medical practice;” if “artists learn to see by drawing, so doctors can learn empathy by putting themselves in their patients’ place” (4-5).

### *Feminist Bioethics*

Clinical and feminist ethics are similar in their attention to case context, empathy, and legitimacy of narrative. However, there are aspects of feminist ethical theory that are not thoroughly delineated in clinical ethics—specifically, attention to power imbalances in medical structures and variations in ethical perspectives. For feminist ethicists, moral theories and principles are deficient insofar as they ignore those cultural values traditionally associated with women. Ethics from a feminist perspective attempt to reconceptualize and reformulate traditional ethics to the extent it depreciates or devalues women's moral experience; such approaches are committed to correcting male biases<sup>1</sup> (Tong 2009). While feminist ethics starts out of female subordination, it need not stop there—it holds promise for others, like patients, whose perspectives are often overlooked. When my poems are examined using a feminist bioethical framework, my subjects (and other patients) are empowered by expanding both the idea of justice and the principlist definition of autonomy to include the feminist conception of *relational* autonomy.

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<sup>1</sup> It is important to note that non-feminist approaches are not necessarily anti-feminist or male biased. Likewise, feminist approaches do not necessarily exclude men or include anti-male rhetoric in their calculations. In addition, there are male philosophers contributing significant work to feminist ethics (Jaggar 2001).

### *Relational Autonomy*

Feminist theorists have suggested a relational model of autonomy, differing from the bioethical standard conception of autonomy generally couched in informed consent (Meyers 1989, Keller 1997, McKenzie and Stoljar 2000). Principlist autonomy has been accused of placing a premium on the potentially masculine ideals of “independence, self-sufficiency, and separation from others, at the expense of a recognition of the value of relations of dependency and interconnection” (Mackenzie and Stoljar 2000, 8). Relational autonomy is instead premised on the fundamentally feminist idea that persons are socially embedded, and that agents’ identities and behaviors are influenced within the context of social relationships and responsibilities (4). In other words, autonomy is simply not possible without social relationships with family, friends, and caregivers—autonomy cannot exist in a vacuum. This follows from the feminist criticism of the self as independent and atomistic, which leads to an overly simplistic (and not too realistic) conception of autonomy.

Justice as a bioethical ideal also stands to gain with feminist ethical insight. While justice according to a principlist framework refers to the just allocation of healthcare resources<sup>2</sup>, feminist theory pays attention to justice on a different scale. At both the individual level and the group level, justice for feminists means equality toward marginalized people and freedom from oppression. With assistance in navigating disparate knowledge and power levels, feminist conceptions of justice are better able to address systemic (and oppressive) conflicts within the structure of medicine. It is important to define “oppression” in this context; a distinctly feminist ideal is that of mitigating oppression. For the purposes of my research, eliminating oppression is embodied in the act of giving voice (via poems) to those whose voices had not yet been heard (my patient-subjects). In Western biomedicine, scientific and empirical ways of knowing—blood chemistry tests, imaging studies—alone hold authority as truth-tellers. The delegitimization of narrative patient ways of knowing about their own bodies within the dominant culture of medicine is suppression of a form of knowledge. This suppression is reductionist—it reduces the patient to a collection of symptoms or

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<sup>2</sup> See Beauchamp and Childress, 2001, *Principles of Biomedical Ethics, 5<sup>th</sup> Edition*, New York: Oxford University Press, pg. 226.

maladies, removing a part of the puzzle, of their story. If a physician is not attuned to the context in which symptoms exist, he or she might be missing a key diagnostic tool.

Illness itself is oppressive. It prevents patients from expressing their full capabilities. Without an understanding of a patient's story, history, and perception of their own condition and body, a physician might be indirectly responsible for continuing a patient's oppression in the form of illness. Without feeling that they are being listened to, a patient might not feel valued. If they do not feel valued, trust suffers, and they might have a pessimistic attitude toward their own recovery or they might not be compliant with treatment. This is harmful to the overall goal of medicine—healing. I do realize that to consider the physician-patient encounter legitimately “oppressive” is a bold stance to assume; however, hierarchical structures based on differing levels of knowledge in the medical encounter are inevitable and feminist ethics is concerned with oppressive systems. It calls into question hierarchies not questioned by biomedical ethics, holding promise for social change.

### *Overview*

Because my claims start with the assumption that medical education and socialization can ultimately be harmful to the healing encounter itself, I will begin this project with a literature review of the process of becoming a physician and its effects. Following my examination of empathy loss during the course of medical socialization, I will examine illness narrative and the narrative medicine movement, which suggests that patient narrative holds promise for improving the healing encounter by cultivating empathy. Poetry and medicine share several interesting parallels—which make it compelling as a creative way of expressing study data for both Herwaldt and myself—and in the subsequent section, I will provide an analysis of poetry and metaphor and its parallels with medicine and illness. Poetry also has interesting implications for ethics. Herwaldt's method—and subsequently, mine—deserves a section of its own, with specifics on Herwaldt's claims, and how I was able to derive similar poems from my own patient interviews. The poems are presented, followed by philosophical analysis. My conclusions with regard to legitimizing both patient ways of knowing and relational conceptions of autonomy rely on ideas derived from feminist ethics, and I include a

review of the literature of the same. Included in that section is an analysis of contemporary principlist bioethical theory and its differences from and similarities with feminist bioethical theory, specifically with regard to autonomy and justice. An examination and explication of narrative ethics and what it requires follows. I conclude with a reassertion of my claims surrounding patient ways of knowing and relational autonomy, and some suggested applications of the *Patient Listening* method.

## 2.0 THE SOCIALIZATION OF PHYSICIANS

Before I present a review of the literature on medical education and socialization, I feel it is important (in the spirit of fairness) to qualify some of the points that I will be making. The sources that I cite in evidencing the indoctrination of medical students might seem to suggest a monolithic type of doctor being created without much apparent qualification of how that training might affect different types of temperaments. These are patterns of training and certainly, not all medical students will react to them in the same way. There is going to be variation in temperament among medical students, but some minimal fortitude of temperament is needed to sustain during long hours and difficult situations. I have no doubt that personality plays a role in the result of medical socialization—in what kind of doctor one becomes in the end. I am not asserting that there is a single ideal temperament that takes to this training and socialization better than others, nor do I feel comfortable claiming that some temperaments will ultimately fail in becoming a tough or an empathic doctor. Those who successfully become physicians are committed unquestionably to caring for people in difficult circumstances.

There are certainly benefits that the existing socialization toward distance can confer. Difficult circumstances necessitate the development of emotional armor for protection. This armor allows physicians to practice medicine without destroying themselves, and in that it is positive. Without a caring, but sufficiently detached, affect, they would have a difficult time surviving and effectively treating patients under stressful circumstances. Development of psychological toughness is encouraged via an embedded element of psychological training. It can also, unfortunately, have a negative effect on the physicians and the patients for whom they care.

### *Pre-med and Medical School*

Examining the education—including the “hidden curriculum,” or the implicit messages undergirding the content that is directly taught—and the simultaneous socialization of physicians leads to exposure of a few dominant themes. From the undergraduate years, competition for grades leads to a singular focus—hard scientific facts—and in the race to stay at the top, more humanistic skills fall by the wayside due to



sheer lack of time and cultivation. The disembodiment of physicians—or the lack of attention to the body of the individual person in favor of the mind alone—begins early, and students learn anatomy along with a certain objectification of the human body, a “separation of soma from persona” (Conrad 1988, 325). This is billed as a survival strategy, and once in medical school, students are not exposed to patients until the third year, when clinical rotations begin. It is a coping mechanism: if students are not able to separate the person from the body, how else are they to dissect cadavers in the anatomy lab, or deal with the instant intimacy that comes with the first patient encounters? It becomes necessary early on for students to “transform the person into a set of esoteric body parts and change their intimate contact with the body into a mechanical or analytic problem” (Smith and Kleinman 1989, 60). This strategy is lasting.

Emotional responses are natural and inevitable in these new and awkward situations, but students learn early on that they are not to discuss their feelings with faculty members or other students, and thus, private feelings remain just that, despite their universality (59). Students develop strategies to manage emotions. Not only are these coping strategies potentially detrimental to the future doctor-patient encounter, they often last long into the physicians’ careers. Students learn to “transform the patient or procedure into an analytic event, accentuating comfortable feelings that come from learning and practicing ‘real medicine.’” (Conrad 1988, 328). This “real medicine” is hard science, technology and procedures. By ignoring the resulting emotions from intimate contact with other human beings, the patients, and often their lives, their stories, and the circumstances that make them unique as human beings are distanced. Discomfort can be managed by irrationally blaming patients, by cruel jokes (“gallows humor”) and by the avoidance of sensitive contact or connection.

When training to become physicians, medical students undergo “dramatic personal transformations, often in a relatively short time, that render them unrecognizable to themselves” (Charon 2001, 84). What can make them unrecognizable can be the loss of the ability to empathize with others, and particularly with patients. Along with the screening of emotion mentioned above, students are ultimately shifting their identification from patients to doctors; from objects and from bodies, to professionals and minds. Affective neutrality (associated with reason) reinforces professionals’ power.

Smith and Kleinman (1989) call development of an appropriately controlled professional affect one element of professional socialization. This control precludes emotion, and in lacking, it becomes more difficult to relate with those who are still in possession of emotive faculties. This is not just implied, it is taught: “students are taught that excessive concern for patients can cloud their clinical judgment, but moderate concern allows them to manage their own feelings and pay close attention to the patient” (67). This “moderate” concern—detached concern—is difficult to achieve and maintain, but because there are benefits to learning how to maintain distance, it is advocated implicitly. A physician overwhelmed and conflicted by emotion and exhaustion, particularly during life-or-death situations when swift action is required, cannot be successful.

### *Internship and Residency*

The years following medical school, the internship year and the years of residency, are notoriously demanding. Hours and hours are spent at the hospital, as inexpensive labor in exchange for learning experience; it is now, when new doctors have precious little time and many patients and related responsibilities, that patterns learned during medical school are solidified. There is a clear and established hierarchy in medical training, and medical students learn from interns, who learn from residents, who learn from attending physicians. The sheer number of patients makes it very difficult to spend any time in consideration of anything beyond immediate biological threat. New physicians are stretched thin. Many learn to cope by taking medical histories and presenting cases to superiors that distance themselves from patients, which is the start of a loss of empathy. “Just the facts” becomes a normative guideline for patient-doctor encounters; “techniques that doctors acquire as interns for managing their caseload evolve into a detached and distant orientation to the doctor-patient relationship” (Mizrahi 1984, 161-164).

As can be imagined, much stems from the sheer number of patients with a demand on an intern or resident’s time. The new doctors learn, often from more senior residents, that it is acceptable to take shortcuts and omit information if it does not seem “directly pertinent to the medical diagnosis” (Mizrahi 1984, 160). What bearing does social condition or patient narrative have that can be considered “directly pertinent” to

biological ailment? In this context, not very much. The role expectations of the medical resident have not been breached if he or she does not choose to sit and talk to a patient, and in this framework, no one will be upset or be held accountable. However, if he or she fails to obtain, for instance, a hemoglobin level, there will be a problem, both with supervisors and the treatment plan. Even if a doctor is particularly humanistic coming in, the more time passes, the more social factors are neglected, until it becomes very difficult to consider such factors relevant.

When these new physicians are responsible for caring for a very large number of patients, unsurprisingly, the disease alone, and its potential cure, is the sole focus. It is the most immediate concern the patient faces, and often one of the easiest issue to address. Not surprisingly, “the actual amount of physical time spent with patients is brief” (Mizrahi 1984, 159). When time is scarce, specific tactics are employed: “patient avoidance, focused interactions, and objectification allow house staff members to manage case-load by restricting range and depth of personal involvement with patients” (162). Interactions can be focused on only the most important issue at a given moment, which might, for instance, be a blood test; not much time is left to address individual psychosocial factors. One must remember that the interns and residents are there to learn, particularly procedures. Patients are in danger of becoming simply means to the medical staff members’ ends: “the doctors were so intent on doing things *to* the patients that they seemed to have little time or desire to do things *for* them” (159).

In addition to recording standard case histories, which instead of life narratives of patients, are simply biomedical specifics, interns and residents are taught the “art” of the case presentation. Case presentation is a minimalist craft. The patients’ experiences are reduced to subjectively “medically relevant” information in order to be presented to instructing attending physicians. “Because it is delivered before superordinates, the case presentation serves as an instrument for professional socialization,” and by this point, the residents have learned what the attending physicians will find medically relevant, and it is most likely not social or familial in nature (Anspach 2005, 362). Compelling beyond the content of the case presentations is their language: these exhibitions use language that further de-personalizes the patient, making the disease again the sole focus. Passive voice is used to mitigate responsibility; the only agents are technology, as in “the CAT scan

showed...” or the MRI indicated...” The patients are presented as less-than-trustworthy in their own stories; they “*state* they stopped smoking” or they “*claim* they have only one drink a day”: the language employed indicates a loss of individual agency and the patients themselves seem to have little truth to offer (Anspach 2005, 365).

### *Effects of Socialization*

The physicians have made strides toward development of a professional demeanor; they have cultivated an air of “detached concern.” The subjective narrative patient history is not seen as possessing much value, and diagnostic technology has the final say. Case presentations have been boiled down to solely “pertinent medical facts.” Humor, often inappropriate, is invoked as a coping mechanism against situations of extreme stress to relieve the tension, which can lead to delegitimization of patient experience and suffering. Patients are discussed in third person, and their objectification furthers the idea of disembodiment, and the afflicted body alone is the subject of attention. The medical chart itself even becomes a surrogate patient: “the chart seemed to be the pivotal point of action around which everything else revolved—ultimately, it was the actual embodiment of the patient” (Mizrahi 1984, 158). What is the effect of these now-ingrained patterns of behavior and coping strategies?

The current system subjects students to long hours of demanding work. The attempt to spend as little time as possible with individual patients seems on the surface to contradict the very reason why the residents became doctors, but it is a way that is developed to lighten the major burden—the patient load. “Distortions of the doctor-patient relationship and negative reactions to patients develop as subcultural adjustments by interns and residents to their work environment,” and as noted, these patterns often last a lifetime of medical practice (156). Empathy can be secondary to the task at hand: to identify the illness and to treat the biological body. Consider science itself as an emotional management strategy: it is a fundamental separation of feeling from substance (Smith and Kleinman 1989, 61). Narrative skills, or the ability to listen to and apply the patients’ experiences to the treatment plan, are difficult to maintain. Pullman et al. (2005) put it well when they observe that the “stethoscope is a most amazing instrument; it can enhance the user’s capacity to hear while decreasing his or her ability to listen” (281).

*Patients as the "Other:" Us Versus Them*

Another result of the separation and objectification that can occur between doctors and patients is the status of the patient as the "other," and the "us" (the doctors, the minds) versus "them" (the patients, the bodies.) This dualism, a function of the socialization process, is fundamentally a coping strategy. Dealing with human tragedy and suffering, as physicians often do, requires a sense of being "untouchable." To be vulnerable, like the patient, could be the undoing of the physician, who must remain safe and healthy in order to retain the role of healer. "By definition, patients are *different*; here begins their creation as medical objects" (Chambliss 1996, 122). Perhaps unintentionally underlying the role of a medical object is delegitimization, which can cause additional suffering and undermine the healing process. Surface differences between patients and medical staff are often myriad (121). Patients can be very old or very young. Doctors possess many years of education and are often highly compensated, while patients' education and wealth vary a great deal. Doctors and patients can differ in religion and social class. But above all, patients are sick and doctors are not. As a result, the doctors hold the knowledge, and the patients are helpless and dependent. Oliver Sacks, a physician who writes of his illness experience, points out that both he and his physician, "in a sense, were forced to play roles—he the role of the All-knowing Specialist, I the role of the Know-nothing Patient" (Sacks 1984, 105). Much of it is in the name of self-preservation:

Staff have good motivations for believing by definition 'we' are healthy and 'they' are sick. They must believe that 'this cannot happen to me' especially when they spend their lives watching helpless people suffer...they may have escaped depression by convincing themselves of their immunity to the disease. Some health workers even choose fields distant from their own personal concerns: men going into gynecology, young people into geriatrics and working with premature infants (Chambliss 1996, 123).

Unfortunately, the result can be disempowering to the patient. This results in patients who are "institutionally objectified: detached from their own lives and life stories" (120).

In the hospital system, other, more obvious barriers separate the ill and the healthy. Sacks (1984) notes the "systematic depersonalization which goes with becoming-a-patient". The ill are dressed in white gowns, and their names are replaced by

identification bracelets. They are subject to institutional rules and regulations, and only doctors can tell them what is wrong, and what to do about it, and only doctors can legitimate them and their illness experiences. In the hospital, “one is no longer a free agent, one no longer has rights, one is no longer a player in the world-at-large” (46). This definitive separation between doctor and patient, between “us” and “them,” is a significant barrier to empathy.

### *Illness Narrative*

Illness narratives offer new perspectives outside of the scientific curriculum of medical schools, and open the door to personal reflection that the “hidden curriculum” discourages. Herwaldt (2008) points out that physicians medicalize everything with regard to the patient encounter in order to protect themselves from vulnerability to the personal experience; however, the “distinction between physicians and patients is a false dichotomy because we are all patients” (19, 15). Echoing the above research regarding the process of medical socialization, Herwaldt, a physician herself, also notes the “dispassionate distance” and the need to remain objective so as not to affect results or become too attached to patients. Indeed, “to become involved with the subject or to be subjective is to do bad work” (12). It almost seems intentional to make normative the coping strategies you have developed to make survival possible.

As I noted above, there are benefits to detachment. A physician caught up in emotion or attachment to a particular patient cannot see clearly enough to make subjective judgments about courses of medical treatment, especially in emergent situations. An overwrought physician is one who is vulnerable to becoming burnt out. Again, however, these defense mechanisms can clearly have negative effects for both patients and the practice of medicine. In contrast to the prevailing wisdom, “physicians are privileged to hear patients’ stories, their secrets, and the most intimate details of their lives” (12). Unfortunately, in the minds of many medical trainees, strength and connection and emotion are mutually exclusive (Coulehan 2006a).

### 3.0 NARRATIVE MEDICINE, PATHOGRAPHY, POETRY, AND EMPATHY

Close attention to narratives of illness can refocus the medical encounter from biology to the lived experience of a person, and my project falls under the heading of narrative medicine. The narrative medicine movement seeks to bring practitioners closer to the stories of illness, highlighting the patient and individualizing care. Patients' narratives of illness are offered as a possible balm to the above complications of medical socialization. Even medical knowledge itself has a narrative structure, and if a doctor is able to see and recognize this, perhaps he or she can validate a patient's story (Hunter 1999, xvii). Rather than just concrete empirical science, "medicine is an interpretive activity, a learned inquiry that begins with the understanding of the patient and ends in therapeutic action on the patient's behalf" (xx). Every patient's story, whether just as a case report upon admission to a hospital, a medical chart, or an entire life history, is a narrative. Illness is not merely pathology; its context is within the narrative of a life. Inquiry and legitimization of patient narratives can increase effectiveness of therapeutic interventions by promoting communication and satisfaction with the medical encounter.

Functional empathy in medical practice takes the form of the clinician figuratively entering and inhabiting the perspective of the patient. As described above, this authentic experience is often lost in traditional medical training. Academics have suggested the reading of literature to develop empathy in medical trainees. The study of literature can help doctors understand experience from the perspective of the "other"; as the physician pays attention to narrative form, and learns to tolerate ambiguity and uncertainty in these stories that have changing and shifting meanings, he or she can apply these same skills when listening to a patient. Charon (2000) writes that literature, by fostering understanding of the human experience, can both develop empathy and promote self-reflection in medical trainees. The physician-trainees' experience of writing and reading "sharpens ethical wits: weighing, judging, developing, and refining personal values," which is clearly of interest to those in medical education (Bolton 2005, 173). Illness narratives, or pathography, hold promise beyond literature for cultivating empathy.

### *Pathography As Narrative Medicine*

If recommended methods of teaching, or encouraging, empathy include “communication strategies, reading literature, writing reflective narratives,” what role does pathography, or illness narrative, play? (DasGupta and Charon 2004, 351). “Literature alone cannot create more ethical and sensitive clinicians,” and pathography—real patient narratives of illness—can fill the void left by this literature (Bolton 2005, 173). Patients are often a resistant object. They “have their own ideas about what is wrong with them, what causes their problems, and how their problems should be treated, all of which frequently contradict the medical understandings of disease and treatment,” and reading pathography forces the physician to recognize this and take steps toward validating differing perspectives (Chambliss 1996, 135). Pathography encourages empathy in a more direct way. While literature is limited by themes that might be rather abstract, pathography has the power to reach the analytical minds of the physicians, minds accustomed to the hard sciences. As pathography is an account of an actual event, it has the potential to reach further for this purpose than fiction. Bruner (1985) makes a distinction between paradigmatic and narrative ways of knowing; paradigmatic is logico-scientific, and it requires formal verification and empirical proof. These scientific ways of knowing hold authority in medicine. In contrast, Bruner’s narrative way of knowing involves stories, drama, human intention, and human action. This is the kind of knowing reflected in patient experience and narratives.

Hawkins (1999), who has done extensive research in pathography, offers a potential use: as an embodiment of the point of view of the patient as part of the healing process, which then becomes accessible to others. She suggests that it may “teach the effects of physician interaction, and therefore assist in the development of empathy by revealing cultural attitudes” (129). Hawkins goes on to point out that pathographies could be “invaluable in teaching medical students, less perhaps to understand the experience of illness—for no written account can replicate what it is like to be ill—than to grasp the importance of the assumptions, attitudes, and myths that patients [and physicians] bring to the medical encounter” (xi). If Shapiro (1993) is correct in that “one cannot therefore fully understand the course of an illness apart from the course of a life history,” medical study and diagnosis without narrative is incomplete (57).



### *Why Poetry?*

Poetry is a distinct form of literature in which language is used for its aesthetic and evocative qualities in addition to, or in place of, its apparent meaning. A poem writ in verse is a creative act, using language as the medium, which utilizes form and specific conventions to both expand the literal meaning of language and to evoke the emotional and sensual. Verse poetry is loaded; it “tends to be so compact, so fully dependent on concise expressions of feeling” (Hunter 1999, 3). Words often have double or triple meaning; it is as if “poems work out a shareable language for feeling, and one of poetry’s most insistent virtues involves its attempt to express the inexpressible” (3). The human dimension of medicine often involves profound pain, profound loss, and profound joy, and “poetry can be the voice of our feelings when our minds are speechless” as a result of these emotions (3). Pathography comes in many forms; in prose, certainly, but also in poetry and visual art. Herwaldt presents *Patient Listening* (2008) as the result of the experiment of applying a creative writing exercise to the patient interview transcripts. There are established (and interesting) parallels between poetry and medicine, introduced above and elaborated below, that made Herwaldt’s method a reasonable choice to frame and guide my application of Herwaldt’s method.

### *Form and Structure*

The nonlinear form and structure of poetry lends itself better to the representation of chaotic life narrative than linear prose narrative. Time does not often pass in a linear way in poetry; time seems circular in that it is hard to define when action or images begin and end. There is value to the circular versus linear passage of time for talking about the illness experience. Linear time is finite and has a definite ending; this can be frightening for one who might be closer to the end. There is a certain comfort in the conception of time as a circle; returning to the beginning means again becoming the person one was before an illness changed everything. This circular sort of narrative resists closure, especially important when closure could mean death. Such narrative commits the ill person as well as the “poet to neither closure nor openness, but to some always-changing relation between the two” (Shapiro 1993, 41). In other words, the “feeling-oriented, nonlinear logic of poetry allows for paradox, and even celebrates it” (Fox 1997, 12).

### *Language*

The abstract and figurative language present in poetry is closer to the abstract and metaphoric illness experience than is prose, and likewise, could possibly capture the illness experience for the purpose of illness narrative more authentically. Such language might be able to better explore suppressed feeling, which does not always come in full sentences. There are limits to medical models for representing the illness experience. In fact, poetry is one way to locate language for obscure experience. In any case, any strong feelings or sensations can be overwhelming and difficult to articulate, let alone during illness. Perhaps such feelings and sensations could be more poignantly conveyed in poetry; “poetic language expresses what plain language cannot” (9). Poetry can be used to explore the ambiguity and uncertainty present and often not addressed in medicine, the constructed nature of medical boundaries, and the experience of social marginalization that can occur with illness. Poetry can help to find words for exhaustion, pain, and cold so profound that words escape. Poets “try to sharpen the sight, to nurture language carefully in the hope of calling upon it for an understanding of what is happening” (Coles 1989, 101).

### *Fragmented Narrative*

In the words of one patient-subject I interviewed: “Pieces and parts together, that’s poetry, isn’t it? Pieces and parts?” Kirmeyer (2000), Montello (2002), and Frank (1995) compare the experience of illness to having a ruptured life narrative—the life as it is known has ended, and it is the job of the physician to put the pieces of the life narrative back together into a cohesive whole. The above patient’s conception of poetry is just like the life narrative of the ill person, in pieces. Fox (1997) asserts that poetry can assist people in reuniting the fragmented parts of their lives. Likewise, Kirmeyer (2000) also points out that “in acute illness, narratives are often fragmentary or undeveloped; where narratives are most coherent, they also may be “formulaic and distant from sufferers’ experience” (153). It would make sense that those coherent, formulaic, and distant narratives would be in prose, which sometimes seems tidier than poetry. Indeed,

just as fragments of poetry can be written with no overarching narrative, or only the briefest strand hinted at, so can we articulate without appeal to elaborate stories of origins, motives, obstacles, and change. Instead, we

may create metaphors that lack the larger temporal structure of narrative but are no less persistent or powerful. Such fragments of poetic thought may be the building blocks of narrative (Kirmayer 2000, 155).

### *Repetition*

Repetition is a familiar convention in verse poetry; when space is at a premium, a single word can carry much weight and hammer concepts home. However, it might serve an important function in the context of personal stories of illness. Those who are ill are dealing in the unfamiliar landscape of medicine and mortality, and repetition of words and images can serve as a psychic touchstone to keep them grounded and centered when the rest of their lives are spinning around them. There are certain unavoidable themes in the arena of illness, as are evidenced above, and latching on to that certainty might be better than having no certainty at all. Here, too, another parallel: “like patients, poets are probably holding on for dear life to some words” (Coles 1989, 100).

### *Illness, Metaphor, and Poetry*

The central argument in Sontag’s *Illness as Metaphor* (1977) is that “illness is *not* a metaphor, and the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking” (3). As Hawkins (1999) has noted, “pathography can be seen as a *re*-formulation of the experience of illness” (24). Both Broyard (1992) and Schultz (2007) through their writing “try to bring illness under control by turning it into a narrative” (Broyard 1992, xiii). In fact, Schultz (2007) writes explicitly that she has “been making sense of illness through narrative, and narratives may be therapeutic in the sense that they impose order and coherence on a chaotic sequence of events” (11). Key for these authors of pathography is that they are both rather anti-Sontag in their poetic promotion of metaphors of illness, both explicitly and through rhetorical devices. Broyard outwardly rejects Sontag’s goal, which is the “elucidation of those metaphors, and a liberation from them” (Sontag 1977, 4). Sontag might not intend to dismiss metaphor of illness altogether; she claims that metaphors, like those of war and battle that have been utilized to talk about illnesses like cancer have done a disservice to the practice of medicine. For Sontag, certain (usually aggressive) metaphors have become so culturally entrenched that they institute practices

that actually deter healing. When something within the body is the enemy, it becomes difficult to separate it from the self. When a therapeutic goal is not achieved, it is hard not to blame the ill person for not fighting hard enough, and this can be destructive.

In spite of this interpretation, Broyard accuses Sontag of being “too hard on metaphor,” and it could indeed be argued that Sontag chooses to address herself more to the “conceptualization of illness than to the daily experience of it”; humans do think in metaphor, and on a smaller scale, metaphor could be a “comforting relief to medical terminology,” a kind of “literary aspirin” (Broyard 1992, 18). Broyard appeals again and again to the “metaphoric and poetic powers of illness,” writing that “we need to make illness metaphorical,” and how “people, if they become ill, must become storytellers, must make a story, metaphors, of their illness” (xii, xiii). Schultz writes of her illness experience, “whose protean metaphors helped to confront and embrace an alien identity” (1). Protean: versatile, mutable, capable of possessing many forms; a “protean metaphor” is one whose significance undergoes a series of transformations that inform the reader in different ways, not unlike the transformation of the author herself. For Broyard (1992), “the sick man sees everything as metaphor,” and he calls metaphor itself a “symptom” of his illness (7, 21). He dismisses Sontag, writing, “technical explanations flatten the story of illness” (66).

Metaphor is an explicit comparison between things not literally similar. When Schultz finds a website advocating for her condition, she “devoured this website; it was the first satisfying meal I had had in nearly four months,” though the website itself is not literally eaten (8). Likewise, Broyard speaks of “eating [a] book for lunch and it making [him] hungry” (12). That book was the “prescription [he] needed that no doctor could give,” as physicians, alas, write prescriptions for pharmaceuticals and not literature (12). Anger and anxiety both are catheters, “inserted in your soul, draining your spirit,” though catheters are more likely to literally drain urine (Broyard 1992, 29, 62). While also not literal, “stories are antibodies against illness and pain” for Broyard, and “every patient needs mouth-to-mouth resuscitation, for talk is the kiss of life” (20, 53). In a particularly poignant example, a patient “died not of cancer exactly, but of pneumonia, as if his lungs had filled with trapped speech and he had drowned in it” (20). There is some specific word play here, and much of it is double entendre—it is difficult to pin down one specific

meaning. How similar to illness, in that there is rarely one certain outcome and interpretation, and conditions and prognoses can change by the hour. As noted above, Broyard, and to a somewhat lesser extent Schultz, employ a great number of rhetorical devices, linguistic flourishes, figures of speech, and wordplay, including and beyond straight metaphor. Schultz offers a compelling reason for such linguistic acrobatics: there is “an essential dishonesty in representing through narrative events that so fundamentally defy order” (11). If pain, nausea, and physical discomfort are so difficult to represent narratively, what other choice exists but to be creative, or poetic?

### *The Ethical Imagination and Poetry*

There is an aesthetic dimension inherent in all ethical decision making; poetry can play a role in clarifying, controlling, and communicating this aspect of medical ethics, and Shapiro (1993) argues that poetry can in fact cultivate the ethical imagination. He defines the ethical imagination as “something within us ‘that doesn’t love a wall,’ that seeks to violate boundaries, transgress borders, challenge our customary ways of thinking and feeling so as to make our rules, systems, habitual perceptions more responsive to a wider range of life,” and he argues that poetry, in whatever form, along with other forms of literature, help to cultivate this ethical imagination (4). The celebration of that which fails to follow a linear or otherwise predictable narrative, the anomalous and the iconoclastic, is crucial. By expanding customary ways of thinking, it becomes more possible to appreciate the perspectives of others. This is crucial to ethics, which are not always normative and often benefit in this way from a narrative approach. Ethical decision-making is a complicated and imperfectly understood process; both poets and physicians have common interest in constructing and clarifying the linguistic expression of social values that impact healthcare; expressions of emotions attached to these experiences help to create value systems that affect medical decision-making (Shapiro 1993).

Poetry is a formal way of seeing, and so is medicine. While suffering from grave illness, there is a “breaking through into consciousness of non-narrativized, inchoate experience that resists narrative smoothing and containment” (Kirmayer 2000, 169). Poetry can get us closer to that experience. Kirmayer (2000) also warns that “talk of

poetics risks aestheticizing illness experience. Yet the use of figurative language to evoke images and feelings and to persuade others of the seriousness of one's suffering is central to the play of meanings in the clinical encounter" (175-176). Likewise, "it appears that the chief imaginative dimension of moral understanding is metaphor" (Johnson 1993, 193). Metaphor is a definitive convention in poetry. It is also found in pathography, as it is difficult to express the extraordinary experience of illness in conventional language. My patient-subjects use metaphor to express their experiences, and it is reflected in their poetry: chemotherapy is described as a "roller-coaster ride" (4.1) and a patient is a little bug, stepped on by "some big thing" (7.7).

#### 4.0 HERWALDT'S *PATIENT LISTENING*

Herwaldt (2008) introduced a pedagogical tool by which patient interviews are transcribed in narrative format, and the transcriptions are then worked into poems by removing extraneous words, and by listening closely to the patients' stories—the rhythm and the emphasis—line breaks are added; the remaining words look like poems on the page, and each word remaining in the poem maintains a concentrated power. She found that the resulting “poems had a concentrated emotional power that the unedited stories did not,” and called the result “‘found’ poems because they are created from other peoples' words” (5). As noted above, the genre of poetry offers a unique opportunity for the capture of the abstract and chaotic experience of being ill, as well as reaching audiences in a new way, which is different from straight narrative that might be tuned out by students or physicians after so many exposures.

Herwaldt notes that she first designed the project to “hear patients' stories and voices and experience their perspectives,” knowing that “patients tell doctors and nurses very personal stories, but healthcare providers often respond with technical answers,” which can lead patients to feel unheard and dehumanized. She hoped that her research could affect communication between patients and healthcare providers in a positive way, and both parties would be more satisfied with their interactions (5). When sitting down to do a qualitative analysis of the transcriptions, she recalled and experimented with a “creative writing exercise in which one writes a paragraph, then deletes words from it, and finally arranges the remaining words on the page like a poem” (4). She found that the poems were able to find the “gist of the patients' meaning,” while distilling the “most powerful words from their prose” by “keeping the most salient or provocative words and heightening their effect with line breaks usually reserved for poetry” (4).

Herwaldt chose to interview patients who had already written and published their own narrative accounts of their illnesses. She hoped that they—already able to reflect on their experiences— “might be able to articulate feelings that for most of us remain buried, inchoate, or inexpressible,” and that healthcare workers who listened to the narratives would be able to identify such feelings in their own patients (3). While an interesting observation and hypothesis led to compelling poetic results, there is a missing

demographic here—an entire population of patients who are either unwilling or unable to write, publish, or otherwise create an account of their illness experience, and it is they who I interviewed for my project. My subjects might have been *unwilling* to produce illness narratives: it might not have occurred to them, or they might feel well enough to do so. These same subjects might have been *unable* to produce illness narratives: they might lack adequate access to education and have poor literacy skills, or they might not have the time or energy or inspiration to write.

Like Herwaldt, I interviewed, transcribed, and “found” poetry by “simply listen[ing] to the cadence of the story and plac[ing] line breaks where they felt right” (11). Close listening is required, required in the same way it might be when a practitioner is listening to a patient narrative in order to determine the origin or process of a disease.

### *The Politics of Patient Listening*

Nothing short of the patients writing the poems themselves can more authentically capture a voice because the poem is solely in the patient’s own words, and because creating the poems requires a close listening of the patients’ narratives (often in a way never experienced before by the patients). The transcribed narrative process remains a close second to the patients’ own work in maintaining power, control, and voice. That said, these narratives (again, in the patients’ own words) are filtered through me, a third party. It might be easier, then, to co-opt the narrative of the subject and make unauthorized changes, knowingly or not. I, as researcher, had “privileged access to and implicit power over the former” (Couser 2004, 17). Indeed, narrative medicine research, and this project in particular, has the potential to “drown out, even as it amplifies” the previously unheard voice of the subject (39). In addition, cultural differences can impact the ability to obtain truly informed consent, on which biomedical autonomy is based. In an ideal medical encounter, patients actively challenge medical narratives about their condition. However, for some vulnerable subjects, such as those who have never before written about their condition, this challenge is difficult if not impossible (32). Without it, the ownership of the life narrative is in jeopardy of being co-opted or altered. To answer this concern, “the more vulnerable the subjects (the less capable of protecting



themselves), the more scrupulous life writers must be about avoiding gratuitously harmful representations of them” (30).

Ironically, there is danger too when we seek to *over-protect* potentially vulnerable subjects: to say that “subjects are necessarily passive and vulnerable in their representation would be patronizing” (202). It is a tenuous balance. In the end, “any inquiry into life writing ethics has to acknowledge that life writing can do good for its subjects, whether they seek it or not” (20). Indeed, “if we were to adopt a notion of harm so broad that any life writing that caused ‘discomfort, humiliation, offense, and annoyance’ was considered unethical, we would be adopting an inappropriately restrictive standard” (29). As work in narrative medicine often has the goal of documenting and witnessing the patient experience, it is difficult to say that such action is always beneficent. The act of documentation might be quite neutral; that is to say, not necessarily for the benefit of the patient. For example, consider documentary filmmaking. The goal of many filmmakers is to simply document an event or a culture, and not to disturb, interfere, or affect—positively or negatively—its subjects.

### *Cancer Stories*

The subjects of my project are all cancer patients. Cancer patients currently in treatment offered me a unique opportunity as a researcher, as they were often receiving chemotherapy for long periods of time, offering time for reflection and interviews. In addition, a cancer diagnosis demands long relationships with oncologists, which both makes the physician-patient relationship that much more significant, as well as offers the opportunity to witness the development of that relationship over time.

My patient-subjects have not written about their experiences. Choosing not to write about one’s experience, or not being able or inclined to do so, shuts out an entire population of subjects. In the end, it might have to be enough to say that for patients who might not be able or inclined to express themselves in writing, but have still elected to participate and have me interview them, having their story come through me—a close and interested listener—might offer some measure of control over their life narratives.

Like Herwaldt's *Patient Listening*, I hope that sharing the results of my research will illuminate patient and caregiver experiences and perpetuate communication and mutual understanding, as well as promote patient control, empowerment, and voice. Patients often lose their voices during illness and resulting medical encounters in the context of the current culture of medicine. Not all patients are able to process and/or write about their experiences like Herwaldt's patients, and it might seem fruitless or even pointless to elicit their experiences again. Giving the patient's voice a forum in a novel way has the potential to not only improve the therapeutic relationship and satisfaction of patient and physician, but also offer unique insights that could inform treatment decisions. Because my research results share the same traits as Herwaldt's in displaying commonness and uniqueness, conversation, and contradictions within the same patient, the call for close listening to patients' stories of illness likewise apply to my subject group.

## 5.0 “FOUND” POETRY

Herwaldt (2008) chose to interview people who had already written and published accounts of their illnesses because she “felt authors who had reflected on these experiences might be able to articulate feelings that for most of us remain buried, inchoate, or inexpressible” (3). Upon initial examination of my “found” poetry, it seems that there is not much of a difference. Just like Herwaldt’s subjects, the participants in my project reflected on the importance of communication and honesty with and from physicians as well as the initial life-shattering shock of diagnosis. My participants express regret over facing mortality. Their lives are changing dramatically, along with their own identities; they discuss losing hair to chemotherapy and role reversal in their relationships. My patients too spoke about their own faith in God, their doubt, hope, and fear. They express frustration and awe at their own overwhelming fatigue and pain and emotion, and at painful and frightening procedures. They worry about possible treatment failure and their own loss of control. They struggle to remain positive in the face of poor prognoses and intimidating odds, and advise others, suggesting remaining positive and trying to digest experiences in small chunks. It seems reasonable to conclude that my subjects investigate these topics to the same depth as Herwaldt’s subjects.

I would like to offer some insight on my creative process in finding the poems within the interview transcripts. There was a certain amount of intuition involved in my creation of the poems, certainly; I have a background in English literature, and in reading poetry comes a certain comfort with listening for poetry in the cadence of patients’ stories. Because I was aware of my intention to find poetry from the beginning, as I interviewed patients, I listened to where they themselves paused while telling their own stories. Their pauses and emphasis is often where they felt they were coming to a key point or a climax, and I tried to reflect those pauses and emphasis when I placed line breaks in the poems. I was able to listen to the cadence of their speech over and over again while transcribing by rewinding and playing again the digital recordings. By the time I sat down with the written transcriptions to find the poems, I had listened to their voices so many times that I heard them in my head as I read their words. I simply placed

line breaks where they did in their speech—the patients knew where they wanted emphasis and I was faithful to that wherever I was able to do so in the remembering.

This is key to my argument of why I am emphasizing my own (and Herwaldt's) method to flesh out the content of the patients' narratives over simply using straight transcriptions of the patients' speech: the listening. I had to listen closely to their stories each time I heard them: in person, in audio recordings, and in print. I had to listen to their stories beyond their content; I listened to their cadence and to their natural line breaks and emphasis. I heard them, and I placed them in the poetry, mirroring and emphasizing their own stories in a way faithful to them. I specifically listened for repetition in my patients' narratives, of both words and themes, and I used the repetition for emphasis, as both a creative strategy and because I trusted that their repetition was intentional. If they wished to stress a word, a point, or a theme, I did so as well in the poetry with the goal of remaining as true to them and their stories as possible. I had to selectively delete some of what the patients said in order to create a more cohesive aesthetic structure, and to convey their stories the most effectively. Again, I trusted my ear. If something was said only once in an off-handed way, or if it was not stressed or emphasized as an important part of a story, I left it out. While others have stressed how important listening is to the medical encounter (Charon and Brody, among others) I am promoting an interpretive method that takes close listening further in a creative way.

My strategy for putting poems into numbered sections was similar to my strategy for determining line breaks. I likewise listened to where stories ended, and where the patients' changed topics, and started new poems where their narrative shifted. I deliberately numbered the poems, and that is where Herwaldt and I diverged. Herwaldt titled her own poems. I felt that titling them would put too much focus on myself and my own creative process and interpretation, and I did not feel comfortable imposing myself on the poems any more than necessary.

**Patient 1 (27-year old white male, Acute Lymphocytic Leukemia)**

**1.1**

Try to get back to some normalcy. Don't play tough guy. Let them know what I need to help me feel better. If you're nauseated, let's get it fixed. Don't fight it. Full communication. That is the key. If I can't communicate with them and they can't communicate with me,

it's not going to work out very well.

Just try to live everyday again, but knowing that this is something that will change me forever.

**1.2**

You are the provider. For a man that is a very big thing, for most men, because of the sense of pride. You want to take care of your family and your wife. Men want to know that they are helping their family, so, when that gets taken away it's different. Now the roles are reversed.

I haven't had time to be emotional about it.

**1.3**

My doctor is very good about not necessarily telling you what you want to hear. He broke it down to what all the possibilities were plus risks and

that's okay, that's his job.  
think you need to know that  
there's not always an upside,  
but at least you're in the know.

It's better to know  
if something's not right. Okay,  
why isn't it right? What are we going to do  
to fix it? That's better,  
I guess. You have no surprises.

Yeah, I would rather have honesty.

He is a physician  
in his case, a specialist.  
It's hard because you can't get real close.  
If he can keep it on a professional level, but  
be compassionate  
by telling you up front,

I think that's all that people want.

#### 1.4

It's not something  
you'd want to wish on anybody,  
including yourself.

You got to get better. You have to be  
really positive. Stay as positive  
as you can.

What do you have to do today  
to make it through  
today?

You can break it down  
into days or segments that  
you can digest.

It's easier that way. With anything  
that you do in life, but  
even more so  
for this.

Faith has something to do with it, too.

## **Patient 2 (63-year old white male, Acute Lymphocytic Leukemia)**

### **2.1**

they drew blood  
at four o'clock in the morning and then  
they were back at six and they drew more blood and  
they drew more blood and  
they drew more blood and  
they kept drawing blood  
they just kept the nurses and the people drawing the blood,  
the doctors kept saying they need more blood

### **2.2**

I pretty much  
knew. I didn't know  
it was leukemia. I'm not a doctor,  
but I knew something was  
wrong.

He said  
how do you feel? I says  
You know, I just feel sort of crappy. I don't  
feel punky. I don't  
have the zip I used to have. So he poked  
and prodded and he said why don't  
we run some blood tests  
to see what may be going on.

He said  
I got some not so good  
news for you kid, he said  
your tests come back abnormal. He said  
we think you have leukemia. Boy,  
they tell you and

it hits you like a ton of bricks.

Sort of first I was in shock. I was  
madder than hell. My emotions  
were just all over the place, they really were,  
they were all over the place.

All of a sudden  
you get slapped upside the head with  
something like this, my emotions  
are just  
    all over the place.

People tell me I'm very,  
very sick.  
I really feel good.  
I'm not sick,  
    that's what I kept telling them.

How could I feel so good and be so damn sick?

### 2.3

You tell him  
what's wrong, and he says  
okay, we'll fix it.  
That's what I appreciate about him.  
Bad news, good news, I don't really  
give a damn, just tell me the truth.  
Lie to me and I'm a wild man. Just tell me.  
I will deal with it. So,  
it's just the way I feel.

It's nothing new, and this disease  
don't have nothing to do with it. It's the way  
I am, it's just my personality. Don't  
mess with me, I don't take that  
well at all,  
never have taken it well,  
never will take it well. I can handle  
bad news though. I can handle that. I can deal  
  
with just about anything. I'll deal with that.  
I'll deal with it.

### 2.4

I just never got comfortable  
with the doctor. I couldn't get myself comfortable  
with him. I always felt  
that there was something  
that he wasn't telling me.



I didn't know what it was. I just  
did not know what it was.

I was one angry  
son of a bitch. I was mad. I mean,  
when I think I am being screwed with  
and people aren't telling me the truth  
I don't take that well.

I am losing confidence  
in this guy, I just don't feel comfortable  
all that's going on. I was losing confidence  
at a record pace.

I'll tell you that the communication  
between that doctor and myself  
was just not there.

It was zero.

## 2.5

Honesty honesty honesty  
honesty. Just be honest, just be honest  
with the patient, my God,  
don't hide anything  
from them. We're in here scared  
you know, we don't know what's going on  
you know, if you don't feel  
they are being honest with you,  
then your mind gets crazy  
your mind gets crazy like oh my God,  
you get scared, you don't know  
what's going on. You know, if the patient asks the nurse  
something or asks the doctor  
something (my God get the answer for them)  
if you know the answer, tell them.  
Tell them.

I don't know about everybody else,  
but I'll tell you this patient,  
I want to know.

## 2.6

First it took me a little bit  
to figure out the pecking order  
around here, you know, my Lord, good God!  
A lot of people involved.  
And I finally figured out the pecking order  
and how things work  
around here, and we started to ask  
a lot of questions.

I was sort of inundated  
with people, more people come to see me  
and I am poked and prodded, but  
I didn't think they were flying  
by the seat of their pants here.

My doctor sat down  
for a good hour, hour and a half  
and took me right through  
the whole thing you know, and  
why they were having the blood drawn, and  
what they were doing. Drew diagrams  
for me, tried to break it down  
that I could understand.

He says  
do you know what they  
are going to do for sure? And  
I said no, not for sure, but  
I have confidence that they  
will know what to do.

I said  
I know they take tests and stuff and  
whatever my tests say,  
that will guide them.

I got a lot of faith  
in God, I got a lot of faith,  
my faith's strong.

I don't know why  
I am going through this, I don't know why,  
but I keep telling myself that there's a reason  
why I'm going through this, I'm not sure what it is,

but there's a reason,  
I don't know what my reason  
is.

## 2.7

I had some  
fantastic nurses, I can't speak enough  
good things about the nurses.  
I really can't. They were just  
great. I was afraid if it wasn't for the nurses  
I would have been gone  
long before that.

Look, I can't be laying in this hospital room  
worrying about my wife, worrying  
about my dogs, worried about this, worrying  
about that, all I can handle is worrying  
about myself right now.

Did I want to come back down here  
today? No, I would have rather stayed at home  
with my dogs. But

I knew I had to be here.

## 2.8

He said,  
what they done, it wasn't  
all lost. Actually what he said  
was a lot of the chemo worked, and  
it did what it was supposed to  
be doing.

You know how doctors are, they  
won't cut each other up, but basically,  
I read between the lines.

The guy didn't know jack shit.

## 2.9

It's okay  
that I have emotions  
I guess. For twenty years

I was on the fire service.  
For twenty years I suppressed every emotion  
I had in my body to do my job. I couldn't,  
    I didn't,  
I couldn't feel for anybody,  
I really couldn't. You talk about  
a bunch of hard ass guys. Firemen are pretty  
    tough, pretty tough guys.

To see what we had to see and  
do what we had to do, you  
    couldn't have any emotions because  
if you did you couldn't do your job. I mean,  
I seen guys who, I seen people decapitated, I seen  
    some of the nastiest stuff of my lifetime. And  
for twenty years I went through that. It took me years  
  
after that to even really cry.

I was a firefighter for twenty years.  
Fought a lot of fire. Was fire chief  
for a hundred and some guys. Retired and went  
into business, and was CEO of companies  
and plant managers, had a lot guys work for me. Had a lot  
of families depend on what I did, to make sure  
I made the right decisions, and always  
was in control. And now

I'm not in control. I'm not in control.  
And I know it.

## **2.10**

I had the heart attack. It was  
the worst experience  
I ever lived in my life. It hurt like  
    the devil,

but once he fixed me  
he fixed me, it was like  
it never happened. The only thing  
was I was in denial, to be very honest about it.

    I was so slick  
that I was in denial. When I went back to see him  
a couple weeks later, he said,  
You're in denial! That's what he said,

You're in denial! He ripped me  
from one end to the other.

He didn't pull no punches  
with me whatsoever, and now I come  
to appreciate what he did, because he knew  
how to handle me.

Guess they thought the old man was gonna die  
but I'm too damn mean for that.

## 2.11

I started getting pains  
in my chest. I thought, ah man, and  
I moved the chair and laid on the couch and  
tried to find a way to get comfortable. Just  
got more pain and more pain and  
I didn't want to call anybody. I didn't want  
to bother anybody and finally  
it just reached a point when I had  
to do something.

As I become more comfortable  
with the doctors and nurses, it's easier  
for me to tell them what's wrong or  
where I hurt.

## 2.12

I had my hips replaced but  
that was sort of a little wear and tear  
on the old body. I got that straightened out.  
I lived in a lot of pain for a lot of years and  
I finally broke down and  
got them fixed, and gosh I felt so dang great  
after that. My Lord, it was like a miracle  
to me to feel that good.

### **Patient 3 (70-year old white female, Acute Myelogenous Leukemia)**

## 3.1

I was just getting really tired  
and it seemed like each day  
I was more tired, and it just seemed like

I didn't have the energy.  
It got to the point where  
when I would even try to make my bed  
in the morning, I would be out of breath.

I just feel so tired  
all of the time

### 3.2

My daddy died when I was eight years old  
and my mother raised us and  
done a wonderful job, and she had her hands full  
with me.

Didn't realize at the time  
how strong-willed you can be  
sometimes, but then whenever I got married  
and started having some children,  
we went to church and  
got saved and  
gave my heart to the Lord, and  
then I realized what an awful time  
I had given my mother. But my mother, she doesn't say too much—  
you weren't too bad.

But I was.

### 3.3

She had come in  
the morning and  
asked me how I was doing. I said  
okay, and everything, and I could see  
she was kind of hesitant. She said  
is your husband coming? And I went yes  
he should be here anytime. She said,  
okay, I'll come back.

He said you've got leukemia. So  
I felt like I run up against a brick wall.  
I wasn't expecting anything  
like that.

I do depend upon  
the Lord. I thought, oh God,

I gotta depend upon you, you  
are going to help me  
through. I just

took a deep breath.

### 3.4

I said  
six months!  
That was hard. I thought,  
six months? That is here  
and gone. But  
whatever happens,  
I am in good hands. I am  
in the hands of the Lord. If  
something happens to me,  
I know where I will be going. I  
will be going to heaven. I  
don't want to leave my family  
down here, but if you have to,  
that's the best place to go. I

sure don't want to go to the other place.

### 3.5

I have a wonderful church and  
I have a wonderful church  
family and  
they were praying for me.

You know that helped.

I had enough prayer, a lot  
of prayer. I mean  
churches all around, even as far as Ohio,  
Oklahoma.

Our God is a wonderful  
God and that's the way our  
God is. And when he knows you  
have to be lifted up, he knows  
how to do it. That really

boosts you up, you know.

### 3.6

He said  
I would like for you to go home and  
enjoy the holidays and  
come up after the first of the year  
to see me.

I had gotten to the point  
where I had no energy and  
really didn't feel good at all. I did  
mash the potatoes and I did  
fix the turkey and the dressing but  
I think that is about all I did  
that day. I fixed cranberries and  
a couple of squash pies and  
I did make sweet potatoes.

I had no appetite. I lost  
forty-three pounds. And I said  
I never did want to lose pounds.

I have always been the kind of  
hefty-type person, and  
I have always thought I need to lose weight  
but I don't guess I ever got really sincere  
about it. If I could just lose so much  
weight, this much of weight, you know  
I'd be happy. But

believe me I'm not gonna worry about  
my weight anymore. I'm

just not going to worry about it.

### 3.7

I've gotten to the point  
where I have just dealt so bad. It was  
really an effort for me to get just get up  
out of the chair and walk  
to the bathroom and  
even back to the chair.

I would be so out of breath.



I couldn't go to church.

It felt like I had  
hit rock bottom.

He called some people and  
they came to the house. My very  
best friend her husband came and  
of course when she walked in the door  
and I saw her I started crying and  
she did too. I said,  
I just feel like I can't go no more.

We met at church. I've been praying  
for God to send me a special friend. God  
sent me you. And I have felt the same way.

We are both very strong believers  
in Christ. She said  
God's here and he is right  
with you and he is not going to let you  
down, and he is not going to let you  
down.

They prayed with us, and she  
got me back up. That's what friends  
are for. God sends you  
your wonderful friends and he knows  
just what you need and  
right when you need it.

He is always right on time.

### **3.8**

When he finally told me  
the day we were sitting in there and  
he was giving me my choices and  
he said you would have six months to live,  
I couldn't get past that. I sat in the room  
in a daze, in shock. My mind wouldn't go past  
that. My mind wasn't thinking anything  
right then.

It took me awhile. I just  
said let me get a hold of myself.

We got through it, and  
we're here now.

### 3.9

Okay, this  
is it. Now we've got to  
face this. This is something  
we've got to face.

He has shown us the good  
side. He has also shown us the bad  
side. I am glad he did. He could have  
just hem-hawed around about the bad  
side, not said anything, and  
I like that he was just so completely honest with us.

Yes, that's what I like. And  
it has really helped us.

We're doing it. And  
we are doing it together as family with  
God. God is bringing us closer  
together. And he is.

Your main source that you can turn to  
is God.

### **Patient 4 (63-year old white male, Acute Lymphocytic Leukemia)**

#### 4.1

It's funny, because  
chemotherapy makes you,  
roller coaster ride.

You're emotional. Sometimes you want  
to cry and at other times you want  
to fight. It's an up  
and down  
thing.

We would sit together  
and discuss the things  
that we were going through,

the things that we were feeling,  
the emotions. Emotions

just are unbelievable. Unbelievable.

#### 4.2

So I went over to the hospital. And  
as sure as God  
made little green apples,

I didn't have any red blood cells. I  
didn't have any platelets. I  
had a whole bunch of white blood cells  
that weren't any good. And  
two hours later I was getting a blood  
transfusion.

That's how we found out that  
I had leukemia.

What do you mean  
I have cancer? I can't have cancer,  
I'm not even sick! Yeah you are  
boy, you just don't know it.

There is some time frame there that you don't remember.

#### 4.3

That's what children  
get. As my wife said,  
that's just more proof  
that I am in my second  
childhood.

So now I'm sixty-three years  
old. I'm laying flat on my back  
in a hospital  
for a month. This stuff has got to  
put me back into remission so  
I can have a bone marrow transplant.

My long term prognosis  
requires it. Without it  
I don't have a long term.

I'm probably going to be incapacitated  
for a total of a year. I'm afraid.

I'm not afraid of being dead. I'm a Christian  
and I know where I'm going. I'm not worried about  
it. I'm not real excited  
about the process  
of getting there.

#### 4.4

She told me I had  
six months. When I told him that,  
he got very upset. He said  
she don't even know for sure  
what you got! How could she tell you  
you got six months?

I grew up down  
in southwestern Oklahoma. Down  
in that part of the world, the most influential people  
are the farmers. They got wheat farmers down  
there that have  
thousands and thousands and thousands  
of acres of wheat. And my doctor looks just like  
one of those wheat farmers.

I made that comment to him one day, and  
I realized that he might think that that was being derogatory  
but it wasn't. It was being very complimentary.

Because they know what they are doing and  
they run the show and  
they are professionals and  
that's what he is.

I have an awful lot of faith in him.

I have an awful lot of faith  
in him. And won't tell you that he's God.  
But I think he calls Jesus Christ and the disciples  
JC and the Boys. He's a pretty good  
guy. He really is.

I told him all things being equal  
I want to be as close to him  
as I can be as I go through this.

I didn't realize it was going to be  
as long as it is, but  
it's all right. I can handle it.

For awhile, anyway.

#### **4.5**

I work in maintenance  
and engineering. I fix things  
that are broken. Don't try to tell me  
or keep me in the dark, tell me  
what's going on. I can handle that.

I can't handle what I don't know.

I'm not a doctor. I can fix  
any machine that's out there, although  
I think of it as kind of like a machine.  
I expect it to do certain things. The problem is  
if I've got bad fluid in a machine, I drain it out,  
change the filters, put in new fluid,  
and go down the road.

It don't work quite that way with the human body.

I deal with things that are broken,  
don't work, need correction, that's all  
I've ever done. The only way I know how  
is to get as much information as I can.

If you got information, you can deal with it.  
If you don't have the information,  
you don't know.

And that's what you can't fight, what you don't know.

#### **4.6**

Okay, let me tell you  
how tired you get. How weak  
you get.

My wife took me in to take a shower.  
I had to have help. Which is quite all right  
with me, I rather enjoyed it. Sick, but still  
a grown man and all that stuff.

She gets me in the shower and  
we get all through and  
I am all cleaned up. Got no hair, so it's not like  
it takes a long time to shampoo your hair.

You just wash your face longer.

I got through and she helped me get dried off,  
and I was too weak  
to put my under drawers on. I had to stop  
and sit down. That's pretty weak.

That's pretty weak.

#### 4.7

It hurts, but  
they don't want to hurt  
you. They're sorry that it hurts  
but there's nothing

they can do about it.

#### 4.8

I'm not a young kid but  
I'm also not old. They talk about treatment  
associated with your age, and they're not saying  
we won't do thing because of your age, but,  
they go around that  
as a thought.

Don't count me out because  
I'm sixty-three. I intend to be around  
a while and I've got a lot of things  
I want to do yet.

I can still put in a hard days' work like I could  
when I was 40 years old.

## 4.9

It's embarrassing. You lose  
all—there is no such thing  
as modesty. You just don't have it.  
But as life goes on, life  
goes on.

Now all of the things that I do and  
all the things that I worry about, that's  
your new normal. That's what you have to learn.  
You learn to expect to go to the doctor, expect  
going to the hospital. That's what you're going  
to be doing the rest of your life.

Because you got cancer.  
And cancer's forever.

You don't get rid of it. It's  
there. You might live a long,  
long time with it,  
but it's there.

## 4.10

They were doing it  
every two weeks, then it went  
to once a month, then  
a couple of times  
every six weeks, then back  
to once a month. All of a sudden

I had an odd reading. It's called blasts.  
I didn't have them for thirteen months  
and then I did.

You've relapsed. That's a totally  
different thing. What do you mean  
I've relapsed? I've been in remission for a year.

I've had the medication, it did the job,  
it took care of the cancer cells. But it didn't. And  
you don't know and  
you don't understand.

The measles and the mumps, you know  
what to expect, and when it's over,  
it's over. Well, with cancer,

that's not the way it is

#### 4.11

I don't know any other way  
to explain it. You cry like a baby,  
for no reason. And you get mad.

I know why you get mad. You  
don't feel like you can fight it.  
I've always been

I TAKE CARE OF THINGS. I'm the guy  
who is gonna get it done. I'll take care of it,  
whether it be work, or at home, or whatever.

And now all of a sudden, I can't.

#### 4.12

Every month I would be back  
in the hospital for four days. They would  
whack me with chemo and I would go home  
and start feeling like I was human again.

You start to feel good? Good, come on  
back, we'll fix that! And you come back  
in the hospital, and they'd give you  
another whack of chemo, and you'd feel  
like you could die but

you'd have to get better. You feel bad  
then you start to recover.



#### 4.13

Ask questions.  
Ask questions. Ask  
every dumb question  
you can think of. Find out  
all you can about the diagnosis.  
Then go back and ask more  
questions.

Recognize what your patients can handle  
and tell them. I recognize  
that every patient is different. If you understand  
your patients ability to deal with  
their illness,  
give them all that they are capable of handling.

#### 4.14

She's there, she supports  
me, she worries  
about me, wants me to get more sleep,  
eat the right things, do  
the right exercises. Don't want to get out  
in the cold, don't want to catch cold.

All the things that someone that loves you  
does, everyday. And we've been married  
a long time, forty-four years. And I had

in my mind to live one day longer than her, because  
I don't want her to have to know what it is like. And now  
I'm afraid I can't do that.

If everything works well, we'll sell our place  
here, and we'll go there and buy us a little old  
house. Live close to family and

pick guitars and  
sing.

#### 4.15

I broke a lot of things. I had  
rotator cuff surgery four times, I broke  
my left wrist, I cut

my left thumb off, I tore  
a muscle in my leg, I kind of beat  
myself up a little bit, my left forearm was broken  
when I was a kid.

I smoked for 34 years

and I don't think that had anything at all to do with what's happened to me.

**Patient 5 (22-year old white female, ovarian cancer)**

**5.1**

She walked in the room and  
she said we found  
a mass.  
Of course when I heard  
mass  
I thought cancer

and thought the world was ending.

She walked out of the room.  
I didn't have any time  
to question her further. I didn't know  
if she was in shock too

of what they found.

**5.2**

That's when I found out it was cancer. I don't know,  
we just cried. I mean  
I couldn't even speak, I think,  
I just sat there and  
cried.

The worst part, I think,  
was the actual diagnosis,  
when I found out. I was in denial,  
I didn't want to believe it.  
I thought, no, they're wrong, the doctors are  
wrong.

I was just in denial. I just remember  
crying. It was probably

an hour's drive home and I just remember  
crying the whole way  
home.

### 5.3

I lost my hair.  
One of my friends threw  
a hair-cutting party for me, so  
that was really nice. It made the process  
a lot easier.

I could just imagine myself, sitting in a chair,  
my mom buzzing my hair,  
all alone,  
crying.

I had really long hair.

No one at the party  
had shaved it, but  
they all got haircuts.

So that was nice.

### 5.4

After she made the diagnosis,  
she asked if it was all right  
to hug me and my mom. She wanted  
us to keep in touch and  
let her know  
what was going on. So she was really good  
even though we hadn't had her  
as a doctor  
for that long.

I would have to say that  
she really did save my life  
right then  
because she found it  
so early.

## 5.5

He was more focused  
on the medical. He was hard  
to understand. He knew  
I was a nurse and he tried  
to talk to me. I didn't even understand  
some of those terms because I was still a student! And  
if I didn't understand it, my family  
was just as confused.

When he explained it, he asked  
me to explain to him  
what he had explained to us  
back to him  
and I explained it.  
That's when my mom started  
taking notes.

He just wasn't—  
I don't want to say  
heartless, that's not  
the right word.

Personable, he definitely wasn't  
personable.

## 5.6

If they had found results, they  
could have known, you know, could  
it possibly have come to my breast? so  
they could have told me, you  
should really consider a mastectomy, or  
a full hysterectomy.

But since they didn't find anything, it really  
doesn't give them anything  
to go on.

You can't see that  
I had cancer. Besides losing my hair.  
Whereas the woman may  
or may not decide  
to have reconstructive surgery for her breasts,  
I have an incision on my stomach.

Other than that, no one would know  
that I lost an ovary.

Breast cancer: people could physically see that  
on the outside.

### **5.7**

I was kind of down and  
wondering why,  
why did this happen? They  
can't give you an answer. That's  
kind of hard, one of the hardest things  
for me. Maybe I could prevent it  
if I knew why I got it in the first place?

Maybe I am doing something daily  
that is causing this cancer?

### **5.8**

The first time I was so,  
so positive. I am going to beat this.  
Now here it is, it has hit  
again. It has just been more trying  
to be as positive as what I was  
the first time.

That is kind of what I am battling with  
right now.

### **5.9**

I know it is hard  
for people  
who haven't gone through it  
because they can't empathize as much.

They don't know what they are going through  
exactly. They can read a medical book  
or a nursing book  
and get an idea, but  
you really don't know  
until you've gone through it yourself.

I think that  
it comes with age too. Maybe they don't know how to handle it  
or how to approach me.  
Even though I have cancer  
I am still your friend. I am still  
the same person.

You truly do find out who  
your real friends are. They will  
be with you forever.

That's a good thing, I've realized.

**Patient 6 (38-year old white female, Acute Lymphocytic Leukemia)**

**6.1**

My husband and I were pregnant  
with twins. There were some  
complications. We were having,  
I guess that would be me,

was having sub-chronic hemorrhage.

She said it could be one of  
three things. It could be a virus, something else  
that I can't remember right now, and  
then she said leukemia.

And I thought well, surely it's not  
leukemia because I felt fine, I was pregnant  
and I was tired and  
fatigued and  
thought it was just due to being pregnant.

She said make sure you bring someone  
with you. I should have known right then  
that it was more important than  
what I was thinking.

She didn't want me  
to go home. I did go home and say goodnight  
to my son. I'm going home. If they are going to keep me  
overnight I am going to say goodnight.

They said, we can wait, and  
I said no, tell me now, I just want  
to know. What is going on?

It was a shock,  
upsetting.

It was hard because we were  
pregnant, and then also, cancer.  
We had worked so hard to getting pregnant, and we  
have tried for a long time. So

angry and sad. Not the whole time,  
but frustrated. Just shocked. Are you kidding me?  
Holy cow, you know.

Angry and sad. Probably mostly sad. We can't  
not be angry. Wouldn't you be angry? Just a little.

Not at them, but at the situation.

## 6.2

In the whole process of things,  
we ended up losing the twins.

It had already started the process  
of losing the twins. They were ten weeks old.

And we had two double whammies,  
the cancer, and then  
losing the babies.

I wanted to wait and  
they said no you can't wait. I said,  
let's just wait a while, and they said no, we can't,  
if you were in your third trimester

it would have been better.

## 6.3

They all made  
handmade flowers because  
you can't have flowers in vases.

They sent them and they made me valentines and  
they sent them at home on a big poster board and  
they always pray.

So I made cookies on Sunday just before I came in  
because I was feeling really good and so I made two batches  
of chocolate chip cookies for sixty kids and

I wrote thank you notes and  
I brought them into school and  
the kids think that's really cool.

#### **6.4**

We got informed really well and  
if you didn't understand something  
the doctors would explain it and  
we've gotten leukemia 101 like in college

so we probably know more about it than  
we probably even wanted to know. I'm glad,  
I like to be informed. If it's happening

to you, you want to know what's going on.

You look up something, then  
you're like Oh!  
you're just like Ah!

I've kind of concluded that I'm not going to look on the internet.

#### **6.5**

I need a purpose to not give  
up. Not that I don't have a purpose  
to live, because I do. I have

my family, and I'm not very old, and  
I want to live a long life and maybe  
someday be a grandma. So

it's good for me to get out and get up and  
come back and get ready and if I don't feel so good,  
I might come back and lay down.



You just have to do normal things. You almost feel kind of cheated. You're on the cancer journey and you're following the rules and

I have to do what the schedule says and it would just be nice to be able to have charge

of my life again.

## 6.6

I'm done with the hair thing but I'll be glad to get my hair back and my eyelashes and everything.

I know that's kind of vain.

I had lunch with my son at school on Tuesday. I went Monday and he said my mom's having lunch with me tomorrow, so I said okay.

I had lunch with him Tuesday and then I came in here Wednesday.

We're sitting there, eating lunch with all the little second graders. He says,

Mom! Show them your hair! Your hair's coming back! And he's trying to take my hat off. They wouldn't have cared. He was excited that my hair was coming back. I don't know.

He didn't really say.

## 6.7

I went out after we shaved my head. I met a friend for lunch.

I had a baseball hat on and we had a server, and it was a girl! A young girl. I found that

she'd look at me and then, if you were my friend, she'd look at you almost like she didn't want to look at me because

she didn't want me to think that she was looking at me. And she was a girl too! I didn't think anything of it until

halfway through and then I told my girlfriend:  
now watch when she comes back, she's not going to really talk to me

or look at me! She will, and then she'll look at you.  
And she did.

## 6.8

I took my hat off. I thought oh,  
I don't care, I was hot. When it gets warmer  
I might not have anything on my head so  
I might as well see the shock factor! Of course  
I had some makeup on, powder. I tried to put mascara  
on, with what my eyelashes are.

I got more double takes from the men than  
I did the women. There was one  
older man. He kind of did a double take.

They just kind of look at you and  
then look away.

I went to Macy's and there was a lady in there,  
she works in the watch section.

I was with my husband. He just likes to go  
with me. Before I could run errands by myself.

He'll make sure that I'm not out too long. This lady walks up  
behind me and she puts her hand on my back and  
she says  
"are you a survivor?"  
and I say "what do you mean?" and  
she goes "are you a breast cancer survivor?"

People think when you have cancer they mostly associate it  
with that. You can't see ovarian,  
you can't see leukemia.

Well, yes, I'm a survivor, but no, it's not breast cancer. You're  
a survivor from day one, so from the day  
you are diagnosed, you're a survivor  
and you're a fighter, and you have to have hope

and faith, because if you don't,  
it's just not good.

When people ask you, how are you feeling  
I thought, do I really tell them how I'm feeling? Or  
do I just say pretty good? So sometimes I just say pretty good, or  
good.

That's all that's expected.

I've had a couple friends go, you're lying, you  
don't feel pretty good. They can tell by looking at you.

That lady at Macy's was a breast cancer survivor. She's  
amazing too.

## **6.9**

So I want to know  
everything. The good and  
the bad, and  
the percentages, and the odds and  
what are my chances for relapse.

I just need to know. I can know, and  
then I know everything that's going on, then  
I feel prepared, in case it does, and  
I just like to know. I mean,

if it's happening to you, wouldn't you want to  
know? When it's happening to you, you would  
remember every little thing.

## **6.10**

It's probably rough  
on him too. The days when I don't feel so good or  
I'm sleeping or  
my head hurts so bad and he'll ask me something and  
I can't think because it hurts from here back to here, and  
he'll want to know something to have my opinion, and  
I'll answer him. I don't know, I can't really think.

It's got to be hard because he's doing things  
that I would normally do.

Dinners. The bills. I'll go home, and Oh my Gosh!  
This bill is due! And I had already lined them up, in order. Or  
I'll try to make the house seem not so messy. I'll do  
some laundry, what I can, and then the dishes and  
the dishwasher. Then I'll come home, and  
things are the same as when I left them.

Because he's helping our son and  
they're coming here and then by the time he does all that and  
he gets him home and gets him in the shower and  
he might put a load in and then he's tired, because  
he worked, and he didn't sleep,  
because they had fires all night.

He's dog tired.

## 6.11

Hope and faith,  
you should have hope and  
faith in god and hope that everything  
is going to be okay.

I hope I'm going to be okay, and  
I hope my friend that has cancer  
is going to be okay because you don't know.

Nobody knows.

When something isn't right, you still  
are gonna think, is it just some cold, or  
am I feeling fatigued because I'm just tired, or  
is it low hemoglobin,

why am I getting bruises?  
Is it low platelets again?

And prayer. We have a lot of people saying prayers, and I  
think prayers are powerful. And I  
think the hardest thing is probably  
asking for help.

People say if there's anything, and  
they'll make ANYTHING really big! and  
they leave their number, call us. If I've  
read that once, I've read that a million times! And

it's really nice. In the future if it happened,  
I would probably call and say,  
let me bring you dinner. I would probably call them directly.

What day can I come? Not that I'm going to call I say  
can you bring me dinner? Because I'm not!

We've had some friends say  
I'm bringing you dinner, what day can I come?

## 6.12

You feel like you're out of control  
things were just so overwhelming  
people were coming in  
different types of people, talking to us,  
it was so overwhelming.

Sometimes they come in rounds  
and there's a bunch of them then the main doctor,  
the attending.

They would come back, just them, and just talk to us  
when they didn't have a bunch of people.

With the doctors my husband asked a few questions  
in the beginning. He said I just wanted to know  
if they had a heart,

you know?

They'll come up and talk to you, say  
how are you doing? Not because they had to  
talk to you, they didn't have to talk to us. We were  
standing in the hallway because we were here in the clinic,  
they're just very genuine.

I've had doctors at other places  
I don't get a good feeling  
you don't feel comfortable.

It's just nice, you know they're capable and  
they're human, and

that's what they're like.

### 6.13

Someone that's compassionate, listens to the patient, and answers the patient's questions. Sometimes if you ask a question they'll give you an answer and then you leave and they totally didn't answer what you wanted to know and you didn't realize it until after you left.

### 6.14

We were eating breakfast. Our family doctor, he's got a good bedside manner. Our son had seen the doctor walk in and it was across the room, and it was not a popular restaurant, it was just a little mom and pop pancake house.

He said can I say hi? and I said just wait. He was with his family.

Part of the way through, he asked again, and I said sure you can go say Hi, so he went and said Hi, and the doctor was looking around to see where we were. We waved and he gets up and walks back and comes to our table and sits down and talks, he sits right next to me.

He sat down and he just chatted with us, which he didn't have to do. He could have just waved. He said I wanted to see how you were doing. I honestly think if I wasn't sick he still would have come over and said hi because he was just so genuine.

They don't have to come and talk to you for a long time. Just that initial hey, and they shake your hand, how are you today, let me tell you what I found out. You're doing great and this isn't so great.

Stuff like that.

## 6.15

I think it's good  
to have a good attitude,  
number one. Of course  
nothing's perfect. When is this  
going to be over? Am I going  
to be okay? Everybody else  
that's gotten sick  
thinks the same thing.

Why did this happen to me?  
I was fine. I've never been sick  
in my life.

We are very happy. Under the circumstances. I mean  
life is good. Everyday is a beautiful day,  
honestly. I mean why not?

Some people have a harder time.

### **Patient 7 (53-year old white male, Hodgkin's Lymphoma)**

#### 7.1

I was bound to the bed, I was stuck

in bed, I was very weak.

All I could do was stay in bed.

Sick to my stomach  
constantly.

It totally wrecked my bodily functions. So it was very uncomfortable,  
drenched in sweat, and I would get up out of bed,

and I would be freezing cold

#### 7.2

You have lymphatic  
cancer.

And sure, it took me by surprise, I kind of started  
asking questions like, what? who, me? why?  
is it because of my smoking? No, no, no.  
Are you sure it's not? Could it have to do  
with my lungs?

It is just out of the blue.  
It picked me to land on. I had questions like,  
    is this genetic? Did it come from my family, or is it  
    just pure luck of the draw?

It came at me kind of quick and  
caught me by surprise. How would you feel  
if you found out you had  
twenty-five percent chance to live?

That's set me back pretty good. I had it  
    bad. Anyway, it came back  
again. That first round of treatment  
wasn't enough.

### 7.3

Now this time it will be different  
because he has already told me up front, he says  
my chances are much less, you know,  
that you will succeed and survive.  
You could die from it, or you know,  
it could cure you.  
I only have about a one in five,  
a one in four chance. That's kind of  
    hard to swallow.

### 7.4

If I had a twin of me  
that had the same thing happen  
    what would I tell that person?  
I would tell him don't ever give up. It's a disease,  
it's one of the curses of mankind,  
of humanity,  
but we have doctors who are smart,  
and they know how to fight it, and they do  
and they will  
but it takes you too. You can't just say, all right,  
give me the drugs. You have to fight yourself. But  
    what would I tell him? Just don't ever give up.  
There is always hope  
somewhere.



## 7.5

Day to day,  
what is on my mind the most  
day to day  
is relief from the discomfort, the pain, the inability  
to do things,  
how it's damaged my body and  
disabled my body. I can't live  
the normal life that I used to live.

I am not complete,  
I am not whole  
because I am disabled  
to a point where I am limited  
as to what I can do physically.

And of course,  
pain.

## 7.6

Thank God for the doctors,  
because they are helping me, and  
they have the know-how. I've got the guts and the will power and  
they have all the brains and  
the tools to do it. Combined,

I hope we can kick it.

I trust his experience and  
his knowledge. He's been doing what he does and  
I trust his judgment, I've been kind of  
following his lead.

## 7.7

I was a little bug that  
got stepped on  
by some big thing. And  
I'm just so small  
and defenseless and  
I just got in the way of something bigger  
than me.

Oh well,  
such is life,  
but I don't let those feelings hang around  
    in my head  
very long.

**Patient 8 (53-year old white male, non-Hodgkin's Lymphoma, T Cell Lymphoma)**

**8.1**

They saved my life here.  
First of all.

And after they saved my life,  
    they've been nothing but  
courteous.

It's like night and day.  
It's like night and day.

I would have rather not needed it,  
but I wouldn't be anywhere  
else.

**8.2**

I was at work.  
Pouring concrete,  
got a phone call on my cell phone,  
    doctor.

He said  
what are you doing? and I said  
pouring concrete.

    and he started laughing. He goes,  
have you ever heard of lymphoma? And I go,  
yeah. Yeah, I have. He goes,  
that's what you got. And I go,  
all right.

Now what?

### 8.3

At least he didn't tell me I was going to die  
anytime soon.

You still got cancer.  
you don't know how bad it is.  
you can't make any decisions.  
you are scared.  
of the unknown.

The unknown scares anybody. But you don't know.  
What you don't know, just freaks you out.  
Especially when it is something to do with your life.

Shocked me a little. You would have thought,  
hey,  
I need to see you in my office,  
we have some things to discuss.

It seemed like he tells people this  
everyday. This  
is what he does  
everyday.

And I accepted it  
as that.

Didn't really bother me  
that much. It didn't really bother me  
that much. But  
I could see how it would bother some people.  
But it didn't me.

### 8.4

I knew something was wrong. The patient  
will know something is wrong with his body  
before you will.

And I surely do believe that.  
There are a few doctors here who agree with me—  
he tells me that right now,  
you know more about your body  
than I do. And he's right.  
I believe him.

Listen to your patient. Listen to your patient.  
Don't overlook anything. Don't overlook anything.

## 8.5

Stay positive, all the good thoughts.  
all of the above, stay positive,  
keep thinking the good things.

You start thinking bad things, things  
will go down the other way with you. I know,  
I've been both ways, I've swung  
both ways, and when  
I think of good things,

my day goes much better.

## **Patient 9 (36-year old white female, Multiple Myeloma)**

### 9.1

I said,  
okay, I said  
are you concerned? and  
the nurse said no, and I said  
okay, in my mind, if you're not that concerned  
then I'm not going to be that concerned  
why create a bill if I don't have to because  
I obviously don't have money to pay for it,  
so I didn't go back.

you really didn't seem concerned  
and neither was I. I will get there  
when I get there.  
You will really need to show me other reasons why  
I should go have this done.

### 9.2

The drug she put me on  
stopped working a month or two after  
she put me on it.

So I went through a couple of extra months of chemo  
without any thing good coming out of it  
because it stopped working. I started it in September  
and it stopped working in October

I went through all of November and  
all of December  
for no reason.

She never caught it.

January  
I was kind of on my own.  
I didn't have no doctors. I didn't know really what  
I was going to be doing or where  
I was going to wind up, so then  
I pretty much went through  
no chemo at all.

I was kind of on my own.

### 9.3

My doctor thought  
I was getting ready to go through my stem cell transplant.  
He ran his tests to make sure that  
we are still up for that and  
that's where we are at and  
explained to me the whole process and  
I went to a class and  
learned about it, and  
he did his blood work and said no  
we can't do that because your levels are not good and  
we are going to have to put you back on  
chemo.

They ran a blood test and  
it came back that it wasn't working and

my cancer is aggressive and

that's two now that don't work, or  
that worked in the beginning and  
then quit.

### 9.4

When I got diagnosed with cancer  
my protein level was 4030, then  
my protein level went up to 5120  
before they caught it, then

my total protein was 6120.  
after a month the cancer just kind of ate it and  
didn't do anything else with it, so  
out of 6120, 5510 of that  
good protein and the bad protein,  
the good protein that your body uses and  
the bad protein that is the cancer,  
out of that 6000, 5510 is all bad cancer, so  
I went from 80% up to 92%  
cancer of the blood

## 9.5

You see so many doctors  
everyday.  
You don't get to see your original doctor  
except for the day you have an appointment  
but you see all these other ones.  
It's kind of confusing.

You have all these doctors  
in training.  
It is hard to question  
what they are doing because  
they wouldn't have made it this far if  
they didn't know what they were doing.

I guess I am not really one to ask  
questions.

That's their profession.  
They know what they are doing so  
why question it?

I kind of just let them do what they think is best  
whether it matches up with the day before. Maybe  
something's changed and they didn't tell me, and  
that's why the plan the next day is something  
totally different.

Like yesterday I was told something totally different  
than today.

## 9.6

His father  
is not involved  
which is a blessing. We left  
a domestic violence situation:  
    alcoholic, verbal, physical, emotional,  
left him to get away from that.

I have a child to protect.

His dad knows I have cancer and,  
    one day,  
he'll put the bottle down and  
offer help.

My son doesn't ask for him, and  
I don't speak about him, and  
    that's about it.

## 9.7

I found out that  
I was adopted when  
I was twelve, living in Chicago, coming home  
from the grocery store. The cashier said  
you can really tell you are mother and daughter  
    because you both look alike. We got out to the car, and  
my mom put my brother and I in the back seat, looked  
in the rear-view mirror, and said  
I have something to tell you guys,  
you're adopted.

I was like okay. And then we went on home,  
put groceries away, and then went on with our day.  
Nothing else was ever spoken about it.

My parents that adopted me were not the best, but  
we all move on.

## 9.8

I wanted to be fixed after  
I had my son, and  
they wouldn't do that. They told me  
some story. You might meet

the man of your dreams.  
If we fix you now, we can't reverse it.

I said,  
unless you plan on coming home with me  
to help me take care of these kids until  
the man of my dreams  
shows up, fix it! And they wouldn't do it.

I've never been  
married. I don't plan on getting  
married. I got one child on my hip, I don't need  
another on the couch too.

## 9.9

He knows Mommy's sick, but  
he doesn't know the full term  
cancer.

We try to sit down and  
talk to him,

he doesn't call me Mommy, he calls me Nana.

He's like Nana,  
you don't look sick.

I'm sick honey, you  
just can't see. I have to go to the doctor and  
there's going to be times I am going to have to stay away  
for them to take care of me. There's going to be times when  
I have to stay away for awhile.

So he knows little pieces, but  
I am all that he has.

I have my moments when  
he goes to bed when  
I cry. That would be my low point.

I have a child that depends on me. So  
he is my high point.



## 9.10

Two weeks after I get home  
I will lose my hair. I'm not too crazy  
about that.

Some women, they don't care, but  
to some women,  
the hair is everything. I don't care  
what I'm wearing, or if I don't match, or  
if I don't have makeup on, or whatever, but  
as long as my hair looks good when I go outside,  
I'm okay!

No hair in two weeks. I'm not too crazy  
about that.

## 9.11

She was kind of flighty. Kind of  
flakey. She never sat still. Every time  
we talked about my ailment she  
never looked me in the eye.

It was always all around the room.

Oh, you got cancer. I'm like okay,  
I'm right here. And every time  
I asked about blood work, she said,  
I don't know. I need to check. I need to look it up.  
I'll get back with you.

Sometimes I don't want to be a name  
on a billboard in the doctor's office,  
a number.

She asked if I wanted a second opinion, she said  
I understand if you do.

I have cancer here. Most likely  
if I go to another doctor,  
I will have cancer  
there too.

I might as well stay here. Why pay  
for the same answer  
twice?

### 9.12

They say God  
will only give you  
what you can handle. I think  
I got my fill. And they say  
what doesn't kill you  
makes you stronger. Did I ask for this? No.  
Did half these people  
in the hospital  
ask for what they got?

### 9.13

I think my body's  
adjusted to it  
pretty well. That's  
some pretty harsh stuff  
that they give us. Heavy  
duty stuff.

It's not Dymatapp from Walmart.

Our bodies are able to take it in  
and use it for what it's for.

The body is a pretty amazing thing.

### **Patient 10 (69-year old white woman, colon cancer)**

#### 10.1

I am a person who has never been sick.  
I had no symptoms whatsoever  
It was kind of a shock.  
I was told on the phone.  
Luckily my middle daughter was  
with me  
at the time, and so what I did was just  
hand her the phone.  
I don't know whether that is quite the best way to do it.  
But it was quite a shock—

I had, you know, no inkling  
that this is what I was  
going to hear.

I wish that my doctor had  
had me get a colonoscopy, before,  
because they could have caught it. Like I said  
I had no symptoms.

## 10.2

The only thing was—  
my mother had a fall when she was fifty-one  
and was a paraplegic.  
she was paralyzed from just below her chest  
and she lived for eleven years.

She was bed-ridden for  
eleven years. And  
she was a remarkable woman. She never complained.

I don't know whether being around her made me strong. I hadn't really  
thought about it.

## 10.3

There are a lot of times when I think, how could I be so sick and feel so good?  
So I don't think about it  
a lot.

They say I amaze them, but it's just,  
it's just a way of life, it's just  
something that I have to do, and I know  
the outcome is not very good, but like I said,  
I live one day at a time, and  
the people around  
make it a lot easier.

you know  
when I come in for chemo, and you know,  
they've got their smiling faces, and they know  
who you are, and they remember,  
and that's important.

So, I think that is the main thing,  
and it's weird,  
but I look forward to it.

I know that the cancer that I have, it's terminal,  
and it's stage four,  
but I'll tell you what,  
I'm going to live as long as I can and as well as I can!

So you know  
overall  
it hasn't been that bad of an experience!

#### **10.4**

She can't figure out where I went  
because when I came to the hospital,  
I was coming to pick up medicine, not  
to remain here.

I had had a Golden Retriever before this one  
for eleven years  
and had to have him put to sleep,  
  
he had cancer.

#### **10.5**

I'm going to lose my hair.  
I never thought I was a vain person.  
I'm afraid I am!  
So I'm not looking forward to that, and you know  
having that happen, having things hit you, having a bunch of stuff hit you  
all at once  
is a little overwhelming.

That was the first time that I really cried or got upset.

### *Thematic Analysis*

I will provide some analysis of the poetry below; a closer analysis of the themes and outcomes could be another project. I do not intend to claim that all patient illness narratives out of which poetry might be found contains these themes, though it is possible to group poems by themes rather than by patient-subject. Many poems fit under several themes. It is also not my intention for this project to draw any conclusions based on theme; my work is more about the narratives and the method than about any specific analysis of the poems themselves. It would have been interesting to have patient feedback on the poetry that was derived from their narratives, but soliciting their feedback directly was not anticipated in my Institutional Review Board paperwork, and is therefore not allowed. My focus is the narratives within the poetry that can inform ethicists and physicians, therefore patient feedback does not fall neatly into my equation.

### *Offering Advice and Regaining Control*

Many of my participants offer advice, both to other patients who find themselves in similar situations, and to physicians. Herwaldt's patients, who had already written about their experiences, and who might have had a pre-conceived agenda coming into their interviews, might not have needed as much prodding for stories and material; some of my subjects did and some did not. The prodding came in the form of questions designed to inspire them to speak more about their illness experiences. I asked a question about offering advice to themselves in the past, to others in similar situations, and to student doctors and nurses, and that is most likely why such content is present in so many of the poems. Regardless, such coaching works in a couple of ways. First, the patient can guide him or herself through the experience, and second, the patient can express a desire to help others going through similar trials. This invitation to help others can also assist patients in transcending their own circumstances, giving them a pragmatic goal on which to focus. They also could have found it more difficult to speak about themselves; for example, patient seven was much more forthcoming when given the opportunity to speak to others. Patient one was very new in his diagnosis, and he offered advice to others on

the little he had already experienced. Offering advice to others is also a way to regain control by focusing attention on a single task. The loss of control is a theme often present in illness narrative.

These subjects also attempted to regain control of their situations by trying to reconcile disparate and seemingly conflicting parts of their lives. Charon and Montello (2001) write about using narrative in medicine to repair broken life stories—one's life narrative is chaotically interrupted in the face of illness. By tying up loose ends and reconnecting the past and the present along a life continuum, disrupted life narratives are reconciled and the ill person regains some measure of control. Indeed for Frank (1995), "people define themselves in terms of their body's varying capacity for control...Illness [itself] is about learning to live with lost control" (30). Sharing illness narrative is an exercise in regaining control. Frank's (1995) narrative wreckage—a life in need of narrative repair—is similar. Illness narrative has to "repair the damage that illness has done to the ill person's sense of where she is in life, and where she might be going" (53). Illness interrupts a life, and illnesses "happen in a life that already has a story, and this story goes on" regardless (54). One of my patient-subjects uses his narrative to reconcile the stark contrast of finding out he has cancer while pouring concrete (8.2). Others speak about the disconnect between feeling well and being desperately ill.

Denial also plays a role in dealing with the loss of control that comes with illness. Some patients do not directly address any loss of control in their own lives. Some face it head-on: noting it, complaining about it, and mourning it. For many, it is connected with gender. Patients 5, 6, 9, and 10 reflect on losing their hair and other physical changes that challenge their femininity. Patient 6 talks about losing both her role as primary caregiver for her son, and her pregnancy due to her illness. Patients 1, 2, and 4 talk about how their masculinity is challenged as they lose their strength and their status as breadwinner to their cancer, and how they must be cared for by others. Both men and women express the vulnerability that comes with illness. Patients 6 and 9 tell stories about their lives tangential to their illnesses. While I might have prompted them with questions, I would have likewise prompted others who did not disclose more about their lives unrelated to their cancer.

I could speculate: they might be afraid of dying and see the interview as a chance to take stock of their lives thus far, they could just be naturally more inclined to think of their illnesses in the contexts of the rest of their lives, or they could just be people who are more open.

### *Metaphor*

In my discussion of poetry and medicine, I included metaphor as an important convention in both poetry and in pathography. There is certainly metaphor in my “found” poetry and it warrants mention. Patients recall being diagnosed with cancer as running into a brick wall. Chemotherapy and emotion that comes with having a potentially life-ending disease is described as being on a roller-coaster ride. One patient talks about fighting his disease as if it were a violent invader. Another talks about feeling like a little bug being crushed by something larger. Some patients naturally moved into metaphoric language, and others did not. It is difficult to speculate on the reasons without being able to follow up with the patients. They might naturally think and speak in metaphor, as part of their temperament, or they might not. They might feel that metaphor is the only way to approach their fear and desperation, when more conventional words fail them. Patients 2, 3, 4, and 7 fall into metaphoric language more often than the others. I am not sure if I would be willing to assert that those poems that involve metaphor are *better* than the others, or stronger. They are different, and compelling in different ways. Those without metaphor are powerful in their starkness, their frankness, and their honesty.

### *Faith in God and in Medicine*

Faith, religion, and God are repeating themes for nearly all of the patients whom I interviewed, to differing degrees. Again, it is difficult to speculate: were these patients religious before they became ill? Has their illness led them to rely on God in new ways? Are they afraid to express doubt now, when they need a higher power most of all, when they most feel out of control? Do they need to maintain faith in order to maintain optimism? All of these ideas are possible. There are interesting parallels between faith in medicine and in doctors and in God. Patient 3 asserts over and over again the role that God has in her life. Patients thank God for their doctors (7.6) and compare their doctors

to God (4.4). Maybe, like patient 9, they feel like they have no choice but to have faith in their doctors, who hold their greatest chance for survival.

### *Relational Autonomy and Patient Ways of Knowing*

Key to the goal for my *Patient Listening* project is both the feminist conception of relational autonomy and the potential for legitimizing patients' narrative ways of knowing. While I will explicate these ideas further in sections below, I want to show evidence of these ideas within my poetic research results. While principlist autonomy has autonomous agents acting on their own behalf without external influence, relational autonomy takes into account how differing degrees of autonomy are possible, and only so in social contexts. My poems reflect the roles that social and familiar relationships play in daily lives of my patient-subjects and in their decision-making. My patients are mothers and friends, husbands and wives who have kids. They struggle to reconcile their own role losses, as they are unable to take care of their children, spouses, their dogs, and even themselves. They have relationships with their doctors and with God. These relationships color everything they do as people, healthy and well. Those around them color their understanding of their conditions and their treatments and all of their decision-making. They are players in social webs of interaction; they do not make decisions as atomistic and independent autonomous entities. These patients are relationally autonomous.

My patient-subjects also seek to legitimize their ways of knowing, which might differ from those of their caregivers, as in Western medical culture it is the perspective of the physician that is prioritized. What is true is what the empirical and scientific data tell us. However, one patient knew he was sick before his physician did (2.2). Another makes an explicit claim that a patient knows what is going on with his own body before his doctor does (8.4). It is this knowing that I seek to legitimize. A physician must be trusted by his patient in order to have a successful outcome; a physician trusting his patient can likewise improve the healing encounter.

The patients that I interviewed doubtlessly accomplished cultural and medical work. Beyond assisting me in learning to listen more closely and allowing me to share my creative results in an academic setting, they have assisted me in making a case for new ways of knowing and for a different concept of autonomy from what is currently



dominant in medical ethics. Some might have regained some measure of control in their own lives by sharing their stories, reconciling disparate parts of their lives, and advising others. Some might have been able to work beyond denial, beginning to size up their situation in ways that could help them heal psychically or physically. They might have become more aware of the work of their bodies during a time that it might feel alien even to them. The interview process could have provided them an outlet, a vent, or a channel for the terrible fear and anxiety that they must be experiencing, allowing them to gain insight and to face the terrible realities of their treatments and even their possible mortality. It is difficult to stand by such bold claims, especially when I am not able to follow-up with the patients themselves, but I can be hopeful.

## 6.0 FEMINIST BIOETHICS AND NARRATIVE

Clinical and feminist ethics are similar in their attention to case context, empathy, and legitimacy of narrative. However, there are aspects of feminist ethical theory<sup>3</sup> that are not thoroughly delineated in clinical ethics—specifically, attention to power imbalances in medical structures and variations in ethical perspectives. When my poems are examined using a feminist bioethical framework, my subjects (and other patients) are empowered by expanding both the idea of justice and the principlist definition of autonomy to include the feminist conception of *relational* autonomy. This feminist relational model of autonomy differs from the standard conception of autonomy in medical ethics generally couched in informed consent.<sup>4</sup> Many feminist philosophers have criticized principlist autonomy as placing a premium on the potentially masculine ideals of independence and self-sufficiency to the detriment of values of relations like care and connection (Mackenzie and Stoljar 2000). Relational autonomy is premised on the fundamentally feminist idea that persons are socially embedded, and that identity of agents and behaviors are influenced within the context of social ties. Autonomy is simply not possible without social relationships with family, friends, and caregivers—it is not possible in a traditional ethical vacuum, which follows from the feminist criticism of the traditional ethical self as independent and atomistic. Justice as a bioethical ideal also stands to gain with feminist ethical insight. Feminist theory pays attention to justice on a different scale: for individuals and groups alike, justice for feminists means equality toward marginalized people and freedom from oppression. In my introduction, I took care to define “oppression” in this context. For the purposes of my research, eliminating oppression is embodied in the act of giving voice (via poems) to those whose voices had not yet been heard (my patient-subjects). In Western biomedicine, scientific and empirical ways of knowing—blood chemistry tests, imaging studies—alone hold authority as truth-tellers. The delegitimization of narrative or experiential patient ways of

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<sup>3</sup> Ethics done from this perspective are feminIST, and not feminINE; both women and men can subscribe to feminist theory. Men can be feminist ethicists and women can be strict principlists. In order to prevent misunderstanding, it is key to point out that feminist ethics is not anti-male, and men have written on feminist topics.

<sup>4</sup> Meyers 1989, Keller 1997, McKenzie and Stoljar 2000.

knowing about their own bodies is suppression of a form of knowledge. Inclusion of this knowledge can enrich the success of the healing encounter.

As I assert above, illness itself is oppressive in that it prevents patients from expressing their full capabilities and living their lives as they choose. Without an understanding of a patient's story, history, and perception of their own condition and body, a physician might be indirectly responsible for perpetuating a patient's oppression by failing to eliminate illness. The feminist goal is to mitigate oppression, wherever it may be perceived.

### *Bioethical Principlism*

If philosophers and researchers are inclined to believe that ethics must “center on analyses of fine-grained distinctions, often so fine-grained that all moral content disappears,” Kuczewski (2007) warns that the potential exists that all discourse regarding potential ethical quandaries will “default to an assertion of autonomy” (419). Respect for autonomy is one of the four principles that guide discussion and debate of much of contemporary biomedical ethics, an approach referred to as “principlism.” According to principlism, human reason discovers, formulates, and applies a system of universally binding moral standards, and these four principles are “often invoked as moral absolutes that contain the solution to any medical dilemma” (Morris 2001, 58). These four principles put forth by Beauchamp and Childress (2001) are respect for autonomy, beneficence, non-maleficence, and justice.

Autonomy is essentially freedom from interference, or literally, “self-rule” (Beauchamp and Childress 2001, 57). The bioethical principle of autonomy recognizes that a competent and rational individual has the right (and perhaps even the obligation) to make an informed choice about his or her own medical care. Autonomous individuals act intentionally, with understanding, and lack controlling influences, and to “respect an autonomous agent is, at a minimum, to acknowledge that person's right to hold views, to make choices, and to take actions based on personal values and beliefs” (63). The embodiment of autonomy in medicine is not simply allowing patients to make their own decisions; the obligation exists for physicians and other healthcare workers to create the conditions that promote autonomous choice.

The bioethical principle of beneficence requires that medical professionals take steps to help others as a positive obligation, while balancing benefits and drawbacks in the interest of utility. Beneficence itself “refers to an action done to benefit others;” these actions can be taken to help prevent or remove harms or to improve the situation of others (166). Adherence to this principle requires that health care providers promote the “good,” acting in the best interests of the person for whom they are providing care. Paternalism, or the cognizant overriding of patient desire motivated by “doctor knows best,” exists as a conflict between beneficence and autonomy. In fact, “whether respect for the autonomy of patients should have priority over professional beneficence directed at those patients is a central problem in biomedical ethics” (176).

The principle of non-maleficence, or “first, do no harm,” dictates that “agents assert an obligation not to inflict harm on others” (113). While beneficence requires the active promotion of the good, non-maleficence “only requires intentionally refraining from actions that cause harm” (115). With respect to bioethical principlism, the principle of justice refers solely to the equitable social distribution of benefits and burdens.

### *Criticism of Bioethical Principlism*

Principlism is, essentially, based on the idea that ethics can be done with a set of four *prima facie* rules, conceived by reason, and handed down in order to derive an acceptable ethical conclusion from nearly any ethical conflict presented. A great deal of criticism of principlist theory, here articulated by Tong (1996), is that the principles are not moored in single universal moral theory, and that the principles (or any rule-like principles) are too removed from the concrete realities of human existence. For Sherwin (1989), there are likewise limitations to the restriction of ethical analysis to the level of general principles. She points to the need to focus instead on contextual details of cases to derive ethical conclusions. Held (1990) asserts that not “all moral problems [can] be handled by applying an impartial, pure, and rational principle,” or rules derivable from it (687). Such abstract principles cannot be applied in all contexts. For Held, principlist bioethical theory can be caricatured as “the advocacy of reason controlling unruly emotion, of rationality guiding responsible human action against the blindness of passion” (683). Donchin (2009) finds the theory formulated from the vantage point of

privileged groups only, and Groenhout (2004) views “rationality” to be often equivalent to the idealized perspective of elite males. While “abstract theories make a claim to neutrality,” it is only a claim (184).

Another key critique of principlism surrounds its exclusive focus on rational cognition. For Le Coz (2007): “on the one hand, emotions can alter our sense of discrimination and lead us to make our wrong decisions. On the other hand, it is known that lack of sensitivity can alter our judgment and lead us to sacrifice basic ethical principles, such as autonomy, beneficence, nonmaleficence, and justice,” which is an interesting paradox (470). Indeed, strictly “scientific and rational reoccupation cannot be sufficient to guarantee the ethical quality of the decision,” and here is the call to emotion (470). Principlism, and examples of both Kantian and utilitarian approaches to ethics, “share a reliance on a highly abstract, universal principles as the appropriate source of moral guidance, and both share the view that moral problems are to be solved by the application of such abstract principles... [these approaches] share an admiration for the rules of reason to be applied in moral contexts and both denigrate emotional responses to moral issues” (Held 1990, 687).

#### *Devaluing of Emotion in Favor of Reason*

In philosophical discourse, emotion is often accused of getting in the way of a rational and reasoned argument. Held (1990) points out the rationalist belief that “emotional attitudes toward moral issues themselves interfere with rationality and should be disregarded” (687). Universal impartiality is valued and emotion must be removed in order to prevent its coloring of ethical conclusions, even if, paradoxically, “emotions are essential to doctors so that they remain sensitive to the great ethical principles” (Le Coz 2007, 471). This hyper-rational devaluing of emotion in bioethical decision-making ignores a very human aspect of real-life ethical deliberation. Empathy, resentment, and anger play a useful role in our moral thinking, and an approach that privileges rationality above all else excludes trust, narrative or “other representational modes of reasoning, rather than acknowledging the stories and images that are powerful tools for making moral sense of the world and our place in it” (Lindemann 2006, 80).

Contemporary principlist approaches to biomedical ethics tend to put autonomy above all, often at the expense of context in individual cases. Autonomy is potentially problematic in that it is difficult to apply evenly to all races, genders, and classes, particularly when there is a large power and knowledge differential, as exists in medicine. Groenhout (2004) writes that “instead of a matter of impartial, absolute principles... ethical experience is fundamentally a matter of care, an affected response to vulnerability” (14). Principlist theories guide hypothetical people who are detached from others, self-sufficient, and equal in social power, and what is morally valuable about them is only their ability to reason. Lindemann (2006) points out that this conception misrepresents most women’s lives because like men, we would not be who we are without the social relationships that shape us but moreover, power inequities can often inhibit higher levels of both self-sufficiency and the ability to reason solely about oneself.

### *The Gendering of Ethics*

In her groundbreaking work, *In A Different Voice* (1982), Gilligan explored how men and women approach ethics in a gendered way, and in doing so, “articulated the sense of alienation many women have experienced in trying to work within the structures of contemporary moral theory” (Sherwin 1989, 58). She found in her research that “men seem preoccupied with developing comprehensive, generalizable, abstract ethical systems which are based on rights, while women seem to be concerned with understanding the specific human dynamics of a situation and, hence, concentrate on particular narrative details with the aim of avoiding hurt and providing care” (59). Men too had the “tendency to view reality as unequivocal and thus to argue that there is one right or better way of seeing” (Gilligan 1982, 683). Ultimately, Gilligan (1982) concluded that standard conceptions of ethics are gender-biased, and there are in fact two different patterns of moral reasoning: one which pursues universal rules in order to ensure fairness and one which is focused on the feelings and relationships of involved parties. In the same vein, Walker (1992) claims that “we need ethics because we need both constructive and critical ways of thinking about political legitimacy, social values, and individual and collective responsibilities;” in other words, a deeply reflexive ethics, able to recognize and interrogate its own social and political impact (34).

### *Feminist Bioethics*

In response to the feminist rejection of the idea of the “ideal ethical reasoner as solitary and powerful—read masculine—judge who applies lawlike principles,” feminists have instead conceived of a cooperative ethical deliberation (Lindemann 2007, 118). While “emotion is not a guarantee of right action[,] neither is it synonymous with irrationality and error,” on which non-feminist approaches to ethics are premised (Morris 2001, 65). Held (1990) writes that reason has been associated with male endeavor, and emotion with female weakness. Not all feminists agree on distinctive feminist virtues or values. There are some significant commonalities however; primarily, feminist ethical frameworks hold that “the history of philosophy, including the history of ethics, has been constructed from male points of view, and has been built on assumptions and concepts that are by no means gender-neutral. Feminists characteristically begin with different concerns and different emphasis to the issues we consider than do non-feminist approaches” (682). In non-feminist ethics, there is a split between reason and emotion and a devaluation of emotion. Donchin and Purdy (1999) put forth two themes dominant in feminist bioethics: “power and particularity—the powers that divide and marginalize non-dominant people, and the particularities and personal lives that resist confinement within externally imposed categories;” these “particularities and personal lives” are embedded in narrative (8). Alcoff and Kittay (2007) summarize feminist approaches to ethics as emphasizing relationality and the use of personal narrative, with a key breakdown of the border between rationality and emotion.

### *Care-Focused Feminist Ethics*

The conception of the feminist ethic of care is attributed to Gilligan’s (1982) work. She saw the rule-based, or justice, perspective and the care perspective as two different ethical orientations: “two moral perspectives that organize thinking in different ways” (683). She claimed that while people might be aware of both perspectives, they tend to adopt only one or the other in defining and resolving moral conflict. For Gilligan,

The distinction between justice and care cuts across the familiar divisions between thinking and feeling, egoism and altruism, theoretical and practical reasoning. It calls attention to the fact that all human relationships, public and private, can be characterized both in

terms of equality and in terms of attachment, and that both inequality and detachment constitute grounds for moral concern (683).

She offers the two moral injunctions of not acting unfairly toward others and not turning away from someone in need to capture and explicate these different concerns.

Relationships between people and the obligations that these create are also central to the care ethic. In fact, “detachment, whether from self or from others, is morally problematic, since it breeds moral blindness or indifference—a failure to discern or respond to need” (686). It is the relationship that “becomes the figure for considering, and relationships are seen to require listening and efforts at understanding differences in belief. Rather than the right to disagree, the speaker focuses on caring to hear and be heard. Attention shifts from the grounds for agreement (rights and respect) to the grounds for understanding (listening and speaking, hearing and being heard). This is a paradigm-shift from rule-based ethics. Indeed, “the capacity to form and maintain relationships... is arguably just as much of an achievement as autonomy, and just as important for moral maturity” (Keller 1997, 154).

An overarching assumption of the care ethic is that it “criticizes impartialist moral theory as being inappropriate for resolving certain kinds of moral problems... care ethics therefore claims that impartiality, following rules, and the use of reason to the exclusion of affect are all inappropriate for resolving certain kinds of moral problems” (154). Care theorists do not accept traditional moral principles above all else, instead pressing for an ethical framework that stresses alternative values such as love, care, and responsibility. They claim that it is these values that can capture the subtleties of context and the bonds of relationships principle-oriented frameworks overlook (Donchin 2009). Relationships are key for feminist theories of ethics. Alcoff and Kittay (2007) write of an agent that is always in-relationship, and Friedman and Bolte (2007) point out that this focus on relationships has moved the relationship to “philosophical center stage, where they now challenge the theoretical adequacy of longstanding ethical norms of impartiality and universality” (83).

In summation, the feminist ethic of care is concerned with actual relationships between persons, and emotion is appreciated rather than rejected (Held 1990). “Caring, empathy, feeling with others, being sensitive to each other’s feelings, all may be better



guides to what morality requires in actual contexts than may abstract rules of reason” (689). Gilligan (1982), Noddings (1984), and Held (1990) accept that caring is morally significant, in fact, the only legitimate moral consideration: “human love, human caring, will be quite enough on which to found an ethic” (29). A care ethic emphasizes family obligations and validates emotional attachments; it focuses on not hurting others, avoiding selfishness and maintaining relationships, context, responsibility, relational and dependant nature of persons, the involuntary nature of crucial care relationships, and inequalities of power (Friedman and Bolte 2007).

### *Oppression*

A defining characteristic of a feminist ethic is the imperative of identifying, analyzing, reducing, and eliminating oppression in all its forms (Sherwin 1996). It can be central, as it is for Sherwin: a “feminist ethics is characterized by the commitment to the feminist agenda of eliminating the subordination of women,” as “the principle insight of feminist ethics is that oppression, however it is practiced, is morally wrong” (1992, 54). Robb (1981) claims instead that such a focus can be tangential, but regardless of its centrality, it is there. A feminist structure of ethics is “capable of challenging the structures and systems that perpetuate women’s disempowerment” (Donchin and Purdy 1999, 9). I have already devoted attention in my introduction and in the introduction to this section to qualifying “oppression” and defining it for my purposes; I define it as suppressing patient narrative ways of knowing, or discounting the perspectives of people on their own bodies.

Relationships are central in feminist ethics, but these relationships too can be oppressive, and those “studied in ethics must attend to the interdependent, emotionally varied, *unequal* relationships that shape our lives” (Sherwin 1989, 62). The empowerment of the oppressed is an ethical issue. There exist many diverse attempts to characterize feminist ethics, but all share some analysis of unequal power (Sherwin 1989). Because feminism itself arises from moral objections to oppression, it must remain committed to the pursuit of social justice as a central concern (Sherwin 1992). Lindemann (2006) defines the term oppression as a “system of institutional forces and processes that keep the members of some social groups from full participation in their

societies” (31). In the context of the medical encounter, oppression can refer to disparate levels of knowledge between patient and physician, with little attempt to disseminate information. It can refer to biases toward certain values in medicine that can be incorrectly assumed to be universal. It can exist in the absence of attempts to empathize and accommodate patients of differing backgrounds, and it can be present when patients’ choices for medical treatment are restricted by the agendas of medical providers.

### *Medical Ethics and Feminist Ethics*

While Wolf (1996) points out that there might not be a single correct or definitive view of the relationship between feminism and bioethics, there are some distinct similarities and differences between the two. As above, she asserts that feminist bioethics is not necessarily a separate bioethics for women, but like other feminist ethics, it must be a bioethics that sees oppression and power and gender as central. It turns out that a care-focused feminist ethic is “readily adaptable to bioethics, where the importance of considering the particular needs of patients and attending to health professionals’ special relationship toward them is already well entrenched in moral deliberations” (Sherwin 1989, 50). In both medical ethics and feminist ethics, there is a sense of frustration with the abstraction and generality that characterizes traditional and theoretical work in philosophy and in ethics, and both share a commitment to evaluating context and allowing for personal aspects of relationships in ethical analysis. Context and narrative are appealed to in both feminist and medical ethics. Indeed, both feminist ethics and medical ethics reflect an interest surrounding particular relationships, in light of the fact that rights and responsibilities are not necessarily universal, instead depending on existing roles and relationships among those who differ with regard to power and status.

### *Similarities Between Medical Ethics and Feminist Ethics*

There are several parallels between non-feminist medical ethics and feminist ethics. Both approaches have made context a valid focus, both understand that influential relationships might not be perfectly equal, and “some authors in medical ethics express a desire reminiscent of feminism to include caring values in their analysis” (Sherwin 1989, 62). Sherwin (1992) points out that, like feminist ethics, the literature of medical ethics

seeks a pragmatic and context-specific approach to ethics. Both fields recognize the limitations of abstractions with regard to moral reasoning for resolving real-life moral dilemmas.

### *Care/Beneficence*

Non-feminist medical ethics also acknowledges the role of relationships. Both non-feminist medical ethics and the feminist approach are critical of the traditional assumption that the role of ethics is to clarify obligations between actors who are “equal, independent, rational, and autonomous” (Sherwin 1992, 82). It is in the biomedical ethical principle of beneficence where a certain acknowledgment of feminist-like care is embedded. Pellegrino (1988) is a principlist theorist who places emphasis on beneficence (or care) above respect for persons as the paramount principle to be considered. Sherwin (1989) corroborates the fact that “there is frequent mention of the need to engage considerations of caring in medical ethics, usually couched in the language of the [obligation of] beneficence that is owed to patients” (60).

### *Centrality of Narrative*

If, like feminist approaches, non-feminist medical ethics has also acknowledged that abstract moral theory as a guide for reasoning is limited for resolving real life moral dilemmas, then what is advocated instead? Patient narrative and context, a narrative approach to moral dilemmas, is encouraged by both frameworks as a better way to make sure that moral deliberation is relevant enough to the real-life relationships and lives that any resulting ethical conclusion will affect. If with narrative, “medical dilemmas are often discussed in terms that appear to rank sensitivity and caring ahead of applications of principle,” than narrative as a tool, rather than rule-like principles, is a better fit for feminist approaches—because it is able to better address the role of context (Sherwin 1989, 60). The trend in non-feminist medical ethics is to examine issues in context and avoid dependence on generalities and abstractions. Theorists in medical ethics likewise find that simple appeals to theory and principle do not offer satisfying analyses and conclusions for the sorts of dilemmas that arise in actual real-life bioethical deliberation. Warren (1989) adds that in medical ethics, more listening is required.

In contrast with applying a general rule or principle, the feminist approach to ethics uses context and narrative to find resolution in textual details (Sherwin 1989). Because feminist ethicists “must call the standing theories into question, a narrative approach to moral deliberation is particularly well-suited to a feminist bioethical analysis of a case” (Lindemann 2007, 124). Both feminist ethics and medical ethics beg narrative, and for feminists, ethical conclusions depend on context. Nothing intrinsically good, or beneficent, or wrong, or evil, and it is here that we can avoid passing judgment without holding *all* of the facts. The “focus on context in feminist and medical ethics helps make evident that the nature of specific relationships is an important element of ethical analysis,” including social context that might be oppressive (61). The “value of narrative bioethics may lie precisely in its power to illuminate the submerged struggles,” which is certainly in line with feminist goals. While it might not be possible to get to the very bottom of the event, it will still help to unfold the implications of experience (Morris 2001, 63). This is what feminist ethics mandates. For those for whom autonomy is difficult or irrelevant—the very ill or the oppressed—a narrative approach to moral deliberation only makes sense for a feminist bioethical analysis, and vice versa (Nelson 1997).

While non-feminist bioethicists work with cases and contexts, Lindemann (2007) asserts that they do not usually approach them in the narrative way that she advocates. For her, case commentators still act as judges, invoking principles or laws that serve as guides to right conduct; once these principles have been derived from the cases, context is of no further interest. In contrast, true narrative approaches require closer attention to context because of what is revealed about the identities of the players beyond just the moment of ethical conflict. Lindemann (2007) also writes that true narrative approaches reveal a “temporal” context, which goes beyond the social. A narrative approach is *expressive* of who we are and who we hope to be, *collaborative* in that it posits not as a solitary judge but as a community of those who need to construct ways of living well together, and *feminist* because it is a means of resisting powerful ideologies.

## *Justice*

Donchin (2009) finds that justice and care are closely intertwined on a practical level. Both non-feminist medical ethics and feminist medical ethics use justice as a principle central to ethical conclusions. However, if for medical ethics, justice is understood as the fairest distribution of benefits and burdens<sup>5</sup>, for feminists, justice becomes understood as freedom from oppression and as respect for individuals in the contexts of their own lives.

## *Differences Between Medical Ethics and Feminist Ethics*

While there are parallels between non-feminist medical ethics and feminist approaches to ethics with regard to care, narrative, and justice, there are enough key differences between them to deem medical ethics less than feminist. According to a feminist critique, traditional ethics implies that, in general, women are not as morally mature as men. In a medical encounter, the same assumption is often made about the patient. Culturally feminine traits like connection, sharing, and emotion are discounted, while “male” ways of reasoning emphasizing rules, rights, and impartiality are preferred (Jaggar 2001). A “sexist ethics would never appear sexist; it would be clothed in a cloak of neutrality;” it would “allow women and men to compete equally for the positions of nurse and physician, without questioning the roles themselves, which were founded on an unequal power relationship between females and males” (Warren 1989, 74-75). In this way, the political dimension essential to a feminist ethic is lacking. If ethical decisions must weigh *all* of the relevant data, and if medical ethics is not considering the feminist goal of identifying and working to eliminate oppression in all its forms, then not considering fully the oppressive power differentials inherent in medical practice is not considering all of the relevant data (Robb 1981). Held (1990) adds that feminists reject a case-by-case approach as is found in non-feminist medical ethics; while both reject abstract rules as a guideline, for feminists, the consideration of cases in isolation ignores patterns and trends in the practice of medicine that can lead to further oppression. Political issues are always embedded in ethical cases.

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<sup>5</sup> See Beauchamp and Childress, 2001, *Principles of Biomedical Ethics, 5<sup>th</sup> Edition*, New York: Oxford University Press, pg. 226.

For non-feminist medical ethics, the primary “relationship question in medical ethics now involves competitions for power, status, or authority [and] relationships are assumed to be fine when there is no overt struggle for power” (Warren 1989, 80). This is decidedly non-feminist. Indeed, principle-based medical ethics “excludes some dimensions of moral experience, such as contextual decision making, special obligations, the moral motive of compassion and sympathy, and the relevance of considering one’s own integrity in making moral decisions” (Calhoun 1988, 688). For Calhoun (1988), principle-based approaches to medical ethics are not considered gender-neutral because the advocated ideals of agency and rational moral reasoning are easier for men than for women to achieve. Some critics add that even if non-feminist approaches to medical ethics do not in principle exclude the ethics of care, if such concerns are not central or directly addressed, it is both inadequate and gender-biased (Gilligan 1982), (Calhoun 1988), (Warren 1989), (Held, 1990).

### *Treatment of Oppression*

If the general feminist objection is eliminating oppression in all its forms, then this is not addressed in the same way in medical ethics (Sherwin 1989), (Lindemann 2006). There exist similarities between the two theoretical orientations with respect to caring and beneficence, context and narrative, and relationships. However, because medical ethics does not “display any commitment to ending oppression,” much of contemporary biomedical ethics “must be judged as lacking from the perspective of feminist ethics” (Sherwin 1992, 84). The concept of autonomy that is central for much of contemporary bioethical debate, rather than “working to empower the oppressed and exploited among us, in practice often serves to protect the privileges of the most powerful” (Sherwin 1996, 53). Because of this, medical ethics is decidedly non-feminist.

Fundamentally, medicine thrives on hierarchical power structures, and it actually tends to strengthen patterns of stereotyping and reinforce existing power inequalities, which is an unintended backlash to the attempt to hold respect for autonomy front and center (Sherwin 1989). Again, without explicitly weighing this in its moral deliberation, medical ethics is decidedly non-feminist. A “feminist ethics of health care includes reflection on the underlying medical views of the body,” and the body, particularly the

feminine and reproductive aspects of the body are medicalized and in this way are medically dominated (Sherwin 1992, 92). The subservient role of patient is feminine: “patients are required to submit to medical authority and respond with gratitude... because feminism is occupied with redefining feminine roles, a feminist ethics of health care takes a natural interest in redefining the feminine aspects of the role of patient,” and no evidence of this consideration is seen in medical ethics (92).

Knowledge is power. It is the physicians who possess the training and the “technical expertise that is essential to sound medical decision-making, but they lack other kinds of knowledge necessary to make good decisions about particular patients’ needs... their medical training does not provide them with special knowledge about the social context in which patients’ needs for health care arise” (154). For medical ethics to be considered feminist, a greater emphasis must be placed on communication and sharing of knowledge. If a physician dismisses what a patient knows from his own experience solely because he occupies a lower position in the cognitive hierarchy, then that is morally wrong, and oppressive (Lindemann 2006).

While feminist ethical frameworks are set up in a way to critique the potentially oppressive structures of medicine, for medical ethics, the “institution of medicine is usually accepted as given in discussions of medical ethics, and debate has focused on certain practices within that structure... the effect is to provide an ethical legitimization of the institution overall, with acceptance of its general structure and patterns” (63). This can have the effect on the lower levels of the hierarchy, who might be oppressed by the structure of medicine, to place even greater trust in the judgment of those above. Feminist theorists must be critical of the fact that medical ethics has remained “largely silent about the patriarchal practice of medicine;” consequently, medical ethics, as it is generally “practiced to date, does not amount to a feminist approach to ethics” (64). Persons do not exist in abstraction apart from their social circumstances, and these social circumstances should not be ignored in reaching ethical conclusions to dilemmas. Ultimately, “moral analysis should examine persons and their behavior in the context of political relations and experiences, but this dimension has so far been missing from most of the debates in medical ethics” (Sherwin 1992, 53). Donchin (2009) adds that the oppressive social

environments that might not be prioritized from a principlist view of medical ethics can easily impair the autonomy that many principlist theorists place front and center.

### *Power and Oppression*

Closely related to the underlying oppression that feminists work to uncover and eliminate (and non-feminist bioethics does not) is the power differential in the medical encounter, which in and of itself can be oppressive. There are significant power nuances at play between physicians and patients in the medical encounter, specifically when there is a gender, class, race, or educational disparity, and the feminist framework addresses these disparities where medical ethics can fail to give them the proportional weight that they deserve in bioethical deliberation. In contrast, for feminists, an important aspect of ethical analysis is to come to a clear understanding of the power structures present and active in medicine (Sherwin 1989). Sherwin (1989) notes that feminist discussions of healthcare warn of the misappropriated use of medical power that can disempower the patient; she then goes on to write in 1992 that a central task of a feminist ethical framework for health care is to “develop contextual models of restructuring the power associated with healing” (93).

The critical point is that,

Theorists in the justice tradition [principle-based models of medical ethics] have not said much, except in passing, about the ethics of care, and are unlikely to say much in the future without a radical shift in theoretical priorities; and concentrating almost exclusively on rights on noninterference, impartiality, rationality, autonomy, and principles creates an ideology of the moral domain that has undesirable political implications for women (Calhoun 1988, 689).

Feminists must explore the contexts within the oft-overlooked system of oppressive practices. Ultimately, without knowledge and understanding of how the interests of relevant parties in an ethical debate may be impacted by power inequity, an analysis is incomplete (Calhoun 1988), (Sherwin 1992).



### *Centrality of Principles*

Another decidedly non-feminist aspect of medical ethics is its overall focus on principles, in accordance with the supposed objectivity of principled thinking (Bowden 1997). Lindemann (2006) likewise criticizes the “impartial, impersonal, universalistic, narrowly rational moral theories that have dominated ethics” (17). Principles often favor a generic, individual subject who is male and privileged, and this theoretical orientation justifies the status quo, inhibiting social change (Donchin 2009). Harms that are experienced by oppressed groups get mischaracterized in bioethical debate as harms experienced by generic individuals, which can misdirect focus and inhibit progress. For Wolf (1996), abstract rules or principles erase gender; for Warren (1989), because theory should be constructed from life experience, and life precedes theory, an overreliance on theory in practical ethical deliberation is flawed. For Sherwin (1992), justice cannot be defined in the abstract. Keller (1997) writes that there is problematic tension between care and autonomy, and for Walker (1992) the emphasis of abstract problem-solving over responses to actual others is problematic. Sherwin (1989) writes that a single theory or strategy should not be considered adequate for settling all ethical questions. Bowden (1997) writes that caring is ethically significant, and it cannot be easily reduced to a single guiding principle. Ultimately, “convincing arguments against principlism do not reject principles but instead reject the claim that principles hold absolutist status as expressions of universal reason” (Morris 2001, 58). Medicine needs to take seriously the understanding that ethics involves more than just principles, and theorists who have written on the use of narrative in clinical ethics can suggest just that (Morris 2001), (Brody 2003), (Kleinman 1988), (Hunter 2001), (Charon and Montello 2002). Despite objections, many feminists do not wish to dispose of all principles to guide action. Some think a framework that incorporates universal principles can constitute one dimension of an adequate bioethical theory, as long as principles are formulated in non-exclusionary terms that reflect the interconnected context of real lives (Donchin 2009).

### *Relational Autonomy*

In bioethics, autonomy is often equated with informed consent,<sup>6</sup> but feminist theory indicates that there can be more than one legitimate conception of autonomy<sup>7</sup>. Providing more information in the interest of informed consent does not necessarily equal greater respect for autonomy; extensive information and alternatives might actually impede decision-making (Dodds 2000). The principlist conception of autonomy is now regarded by many feminist ethicists with suspicion; some writers have identified the concept of autonomy as inherently promoting masculine ideals of reason and self-reliance (Mackenzie and Stoljar 2000, 3). The human values, social practices, relationships, and communities that are based on cooperation and interdependence can even be seen to threaten or compromise this conception of autonomy (6). Respect for autonomy is cashed out in respect for “rational” medical choices, and this notion of rationality and autonomy is a “historically, socially, and culturally specific ideal that parades as a universal norm” (11). Principlist conceptions assume that individuals are equally rational and equally able to reflect once given adequate information (Dodds 2000). Therefore, the rational competence of certain groups is often questioned because they might lack emotional distance and the objectivity to act rationally, and therefore even possess autonomy at all. Recognizing the complex connections among individuals with regard to society and culture, some feminists theorists are now promoting instead a relational model of autonomy that stresses the human web of interconnected relationships, the social norms and pressures that influence medical choices offered to patients, and the obligation of health care providers to promote patient autonomy (Donchin 2009).

Donchin (2009) notes that oppressive social environments, illness, or trauma can easily impair autonomy. An ill patient does not much resemble the autonomous ideal: independent, unconnected, self-interested and self-reliant, unconnected to others, interchangeable and impartial, dispassionate, detached, and in a position to advocate for themselves. Conditions within which medical decisions are made are far from the rational ideal of autonomy, and such decisions are not made as isolated and rational atoms (Dodds 2000, 222). When human webs of relationships surrounding patients are examined,

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<sup>6</sup> Dodds 2000, Lindemann 2006.

<sup>7</sup> Mackenzie and Stoljar 2000.

intimates most closely involved in their care are revealed, along with a more nuanced account of how best to respond morally (Lindemann 2006). Without this consideration, the diversity and complexity of individuals is pared away and agents are reduced to interchangeable sameness (Mackenzie and Stoljar 2000, 6).

Because individuals differ so significantly in their talents, capacities, character traits, values, desires, beliefs, and emotional attitudes, one single blueprint for what constitutes an autonomous life is not possible (Mackenzie and Stoljar 2000). If we think of autonomy as characteristic of agents who are “emotional, embodied, desiring, creative, and feeling,” *as well as* rational, we might see that autonomy can only be developed in the social context (21). Friedman and Bolte (2007) define the feminist relational version of autonomy as one that “focuses on the social context in which autonomy emerges and on the social nature of the self who realizes autonomy... thus treat[ing] social relationships as necessary for the achievement of autonomy” (89). An understanding of autonomy as connected to informed consent is a physician-focused autonomy, presupposing that ethical concern should be directed to the actions of the physician in providing information and obtaining consent and not to the decision-making process of the patient (Dodds 2000). Relational autonomy brings the focus back to the patient, and his or her social networks and understandings that influence his or her own unique autonomy.

In addition, “there are good grounds for critically examining the ways in which the dominant conception of autonomy used in bioethics may contribute to the systems of oppression” (Dodds 2000, 223). A relational understanding of autonomy can address forces of oppression where non-feminist bioethics falls short. Relational approaches are concerned with analyzing the role that “social norms and institutions [medicine], cultural practices, and social relationships play in shaping the beliefs, desires, and attitudes of agents in oppressive social contexts;” in fact, oppressive social environments can impair agents’ autonomy in this way and at this level (Mackenzie and Stoljar 2000, 22). Donchin (2009) writes that feminist approaches capture contextual subtleties and relational bonds overlooked in principle-based frameworks; I propose that relational autonomy does the same for bioethical autonomy. It is a more robust conception of autonomy that pays due

attention to context. Autonomy defined solely as informed consent allows patients to choose “freely” from restricted options.

### *Relational Autonomy and Trust*

O’Neill (2002) asserts that the promotion of traditional individualist autonomy is detrimental to trust within the medical encounter. Autonomy identified only as individual independence can lead to “ethically dubious or disastrous action... trust is surely more important, and particularly so for any ethically adequate practice of medicine” (xi). For O’Neill, promoting only the traditional, individualist, and principlist conception of autonomy is inadequate. Holding individualism and solitary decision-making above all in medical contexts undermines trust in medicine as a whole. She posits that some conceptions of autonomy and trust are compatible. The conception of autonomy that I seek to promote—one that is feminist and relational—goes beyond compatibility. It actually promotes trust. It undoubtedly took a great deal of trust for my patient-subjects to share personal, painful, and intimate details of their lives with me, a perfect stranger, during the stressful and frightening experience of illness. The bond that was created, if only for an hour or less, was crucial to the project and to my goals. My research process contributed to the empowerment of my patients by elevating them to a new level of *relational* autonomy through the cooperation that occurred during our interactions. The trust that was necessary in our encounters supports both the trust that O’Neill (2002) finds essential to the effective and ethical medical encounter, as well as the specific conception of autonomy that I seek to promote.

### *Relational Autonomy and Patient Listening*

A relational conception of autonomy differs from the standard conception of autonomy as informed consent. The standard conception demands reason, dependent on self-reliance, independence, and freedom from interference. In contrast, relational autonomy is premised on the interdependence we have with those close to us—our families and social groups—and others—our medical caregivers—and how they affect and influence our every decision. Through the trust that I cultivated with patient-subjects during my *Patient Listening* project, I became part of their social networks (like those in

which we are all embedded) if only for an hour. While autonomy as informed consent depends on a strict definition of reason or “rational” medical decision-making, my research introduces a new, broader concept of reason or rationality, in which reason-in-autonomy does not exclude others, but rather includes the influence and input of others within the social webs that we as humans cannot escape or deny. A relational conception of autonomy is a better moral option for patients in pursuing medical treatment and making medical decisions. This morality can be based in a different and more pragmatic kind of reason that necessarily takes cooperation with others and interdependence into account. Relational autonomy is still a relatively undefined term for feminist theorists, and my research sheds new light, contributing to its analysis and its depth.

### *Conception of Justice*

If justice for non-feminist bioethicists is found in the equal distribution of resources and benefits and burdens, then a feminist understanding can enrich justice itself with the idea of justice as the freedom from oppression. Groenhout (2004) explains that,

human lives are never self-defining and self-sustaining in the ways that would be needed for neutrality to make sense. Humans have limited abilities to care for themselves, and they are dependent on the others around them to support and provide for them. Given this finitude and dependency, abstract justice, with its fiction of absolute independence, cannot offer a version of how we should arrange our lives together to provide for the support we all need (85).

The feminist ethics of care assumes that humans are relational beings whose families and situations and socialization create context. Care ethics adds to abstract conceptions of justice, insisting that the “finite, dependent, situated, and relational nature of humans” figure into our calculus and understanding of justice (178). In order to adequately evaluate concerns of justice, we must “analyze and construct social institutions that take into account the needs and interdependencies that are a part of human life [and] recognize that humans come in a broad range of ages, social situations, and dependency conditions” (178). Inattention to social context in ethics cases also serves to maintain unjust social hierarchies (123).

Feminist bioethics, however, does not dictate a complete overhaul of justice; ethics of care does not reject the basic aspects of principlist accounts of justice, such as rights. Rights are an important concept for any conception of justice, but they are not sufficient as an account of what justice requires (180). Lindemann (2007) asserts that bioethicists have not yet fully availed themselves of feminist resources for critique of medical practice; medicine ought to be of particular concern to feminists, as it commands great prestige, authority and power, and therefore potential for abuse. Justice, in the context of my research, is couched in making voices heard: patient voices, particularly embedded in social context.

### *Patient Listening and Feminist Ethics*

Clinical medical ethics and feminist ethics share some commonalities, particularly with regard to case context and legitimacy of narrative, however, feminist ethics has still more to contribute to medical ethics with regard to conceptions of power, autonomy, and justice. A feminist-inspired model of relational autonomy takes into account that humans do not exist in vacuums, but instead in “enmeshed relationships of interdependence” (Groenhout 2004, 10). We exist in complex webs of relationships and responsibilities that shape who we are and what we do, and not as solitary, individualistic, and solely rational agents. Autonomy as informed consent pays no attention to context, “ignoring background conditions that patients bring to their medical experience” and “institutional power relationships that influence their opinion” (Donchin 2009). My poetic study results are full of context and evidence of the relationships from which patients are inseparable, and which influence their every thought and decision. These enmeshed agents are evidence in favor of a feminist relational autonomy.

A feminist-inspired bioethics more effectively addresses systemic injustices in the medical establishment impacting our ability to consider other ways of knowing beyond the empirical. Closer attention to power relationships can lead to new understandings of autonomy. A feminist approach would pay more attention to justice and equality toward women and other marginalized identities. A full commitment to justice requires more than attention to allocation of resources and universal benefits and burdens. A system that legitimizes only one way of knowing—empirical and scientific—and that discounts

entirely a different way of knowing embodied in patients themselves and their relationships is lacking. Identifying problematic structural failures is the first step toward the feminist goal of promoting justice and mitigating its opposite.

## 7.0 NARRATIVE ETHICS AND NARRATIVE TRUTH

A system of ethics conceived of using narrative is called “narrative ethics,” and this project fits within this system. As has been discussed at length above, many forces restrict physicians’ abilities to reflect on their clinical experiences and relationships, and this medical practice without reflection is unable to grow and become more humane. Both Charon (1991, 2002) and Hunter (1991) have observed that both the practice of medicine and the structure of medical knowledge are themselves narrative-based; the narrative medicine movement seeks to bring practitioners back, closer to the stories of illness, to more effectively treat patients and bring about healing.

### *Narrative Competence and Narrative Responsibility*

Narrative competence is, as defined also by Charon, the “set of skills required to recognize, absorb, interpret, and be moved by the stories one hears or reads” (2004, 862). The practice of narrative medicine in all of its forms can increase narrative competence, and development of narrative competence allows for a more ethical treatment of the narratives of patients. Consider also cultural competence, defined as a set of skills utilized to interact effectively with people of different cultures; it is similar to the concept of narrative competence, which requires those in possession of it to listen to, and analyze, stories. In order to be culturally competent, one must possess an awareness of one’s own cultural worldview and attitude towards cultural differences. It is important to note that allopathic medicine has a very distinct culture of its own. One who is versed in cultural and narrative competence must possess a knowledge of and interest in different cultural practices and ideas, and a measure of curiosity, flexibility, and empathy. “When a doctor practices medicine with narrative competence, he or she can quickly hear and interpret what a patient tries to say;” working toward this kind of competence results in an ability to understand, communicate with, and effectively interact with people across cultures and ideologies regarding their individual and cultural experiences of illness, ideally toward a more ethical end (862). The concept of narrative responsibility refers to a set of important ethical implications. As each person plays a part in the life stories, or the narratives, of others, one must be mindful of one’s impacts. Each person bears responsibility for the



roles they play in the narratives of others; it helps in understanding to frame these interactions as the “joint construction of mutual narratives” (Pullman et al., 2005, 281).

Narrative competence and narrative ethics are definitively linked. A poignant example is the narrative of Lia Lee. Fadiman’s *The Spirit Catches You and You Fall Down* (1997), is both a rich narrative and a warning. Lia Lee, a young Hmong girl living in Merced, California, is in a persistent vegetative state as the result of severe epilepsy, and the narrative brings up issues of narrative competence, and the lack thereof, in contemporary medical care. There was a fundamental crisis between Lia’s physicians and her culturally Hmong family and community; they spoke two different languages, literally and figuratively, and it was this lack of communication on any practical level that was the beginning of the end for Lia. The doctors’ understanding of Lia’s illness was vastly different from that of her parents and no effective attempt was made to bridge the divide. In the Lees’ minds, it was the very anticonvulsant medication given to tame her disease that was causing her problems: “Lia got very sick and I think it is because they gave her too much medicine” (148). Conventional attempts to bridge the cultural divide failed. Even the “counseling sessions, which usually left them confused and angry, were intended to reduce their stress” (150). The Lees were found to be “non-compliant” in administering the anti-convulsant medication to the child, with disastrous results: she was removed from the care of her parents for a time, a traumatic, and perhaps unnecessary, situation for both parties. The conflict between Lia and her doctors went beyond ideas of compliance and non-compliance. The Lees simply lacked the frame of reference to understand Lia’s condition in the Western context. As refugees, “violence, starvation, destitution, exile and death, were, however horrific, within the sphere of known tragedies. What happened to Lia was outside that [imaginable] sphere” (171). There was no meaningful attempt at communication, no meaningful consideration of narrative, or social factors, or oppression, or power. A lot of questionable ethical conclusions led to a catastrophic conclusion.

### *Narrative Ethics*

Medicine practiced with an understanding of narrative ethics ideally leads to narrative competence, which according to Brody (2003) cultivates “philosophical understanding of what it means to be sick, for ethical guidance, and for improving the quality of health care and the education of health professionals,” and this goes beyond giving the patient a voice and sense of power (2). As the use of stories in medical theory and practice is considered narrative medicine, medical ethics conceived of and practiced using stories is called narrative ethics. Narrative offers tools that take into account the subtleties of perspective and the human aspects of ethical dilemmas not addressed by strict principlist-based medical ethics alone. Much has been written about using stories of illness as tools for ethics, but in this context, suffice it to say that there is an intuitive component, in that “narrative elements are deeply embedded in moral reasoning,” and there is legitimacy here in that “responses to narratives are the grounds out of which our principles and theories grow” (179). The “characterization of narrative ethics as opposed to ‘theory’ is not so straight forward, however, since narrative ethics is a theory” (Rees 2008, 163). Difficult ethical decisions can often benefit from a narrative approach in the pursuit of resolution. When there are no clear answers, such as laws or principles dictating moral responsibility, sometimes another way of knowing is needed—an epistemology different from the empirically-based medical paradigm. “Narrative in a general sense thus describes any turn to writing about experiences of medical care as a means to accomplish ends that concern more than the ends of medicine itself,” and an end more than medicine itself is ethical (165). Ethical dilemmas often end in a mix of failure and success, which is difficult to accept for the traditional black-and-white medical paradigm. A narrative approach can ultimately promote the ability of the patient to continue with her life story, honoring her individual narrative. In fact, in general, “medical ethics continually draws on narratives of incurable disease, bodily disfiguration, denial of desperately needed services, premature or wrongful death, systematic injustice, and tragic loss. Without these narratives of embodied human suffering, medical ethics couldn’t happen” (166). The narrative component is already there.

Like feminist conceptions of ethics and unlike rule-based ethics, narrative ethics allows for emotions in its calculations. Morris (2001) directs us to consider that the emotion inseparable from narrative is valuable in that it can be a resource in the formation of moral knowledge and, therefore, ethical action. Narratives work on us by engaging emotion, and that emotion is vital to the creation of ethical knowledge (Morris 2001, Nussbaum 1986). Morris (2001) writes that the fact that habit requires us to put reason and emotion into separate words and unconnected categories is a mistake that has implications for ethics, because thinking, and in this case, ethical reasoning, involves a crucial collaboration with feeling. In fact, an ideal “narrative bioethics would look beyond a calculus of principle and reason... to account for the emotion so crucial of ethical action” (68). Reason and emotion share roles in the creation of moral knowledge and ethical action. In fact, “unacknowledged narratives inseparable from our personal identities may matter as much as principles in our everyday moral acts” (71).

The point of departure for narrative ethics is the idea that ethics does not exist as a set of disembodied principles but rather is embodied in the stories people tell about the lives they actually live. The “best way to read the data of bioethics is through the tools of what they are: that is, narrative;” bioethics cases are narratives, so to only apply ethical theory without narrative theory is a mistake (Chambers 1999, 19). Humans are imaginative moral animals, and it is narrative that makes it possible to explore and reflect on consequences of decisions and commitments (Johnson 1993). Medicine and narrative are one and the same: medicine is filled with life and death human drama (Hunter 1991, Morris 2001). A narrative bioethics directs us to consider the “novelistic clash of voices, dialects, and values” present in any given medical encounter, and would not consider a case decided as soon as one character deems another unethical, reminding us to examine what has been unsaid<sup>8</sup> (Morris 2001, 63). Narrative ethics brings moral theory down to earth and addresses both of the feminist requirements of acknowledging and working toward eliminating oppression and helping us to see the nonmedical social narrative affecting ethical decisions (Morris 2001).

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<sup>8</sup> See Fadiman’s *The Spirit Catches You and You Fall Down*.

Much of narrative ethics is theoretical and analytical, but there is a creative branch where this project will fit: there exists the need for an ethics “attentive to everyday encounters and responsive to values submerged in the personal experience of illness” (70). Charon and Montello (2002) suggest that narrative approaches to ethics recognize that the “singular case emerges only in the act of narrating it and that duties are incurred in the act of hearing it” (ix).

### *Narrative Truth*

In Western medical culture, the analytic and empirical are celebrated, with intuition of patients deemed invalid. Evidence-based medicine reflects the historical bias toward the analytic and explicit, while discounting the actual art and science of the practice of medicine: pattern recognition in diagnosis, non-verbal cues, and the doctor-patient relationship. In medicine, science—machines, tests, imaging studies—are the sole bearers of truth. Hawkins (1999) addresses the construction of narrative truth as “the task of an author of pathography...not only to describe this disordering process but also to restore to reality its lost coherence and to discover, or create, a meaning that can bind it together again” (3). Here, power is reclaimed from the illness and the medical culture that has taken it, and voice and agency are restored to the person possessing the disease in the body in the bed. Hawkins finds validity in differing representations of truth: in the parallel and opposite dramas of illness narrative and medical case study. In directly discussing the idea of narrative truth, she determines that “true stories” are chronicles and interpretations of life (1990, 14). Frank (1995) defines narrative truth as the “reconnection between past and present... out of narrative truths a sense of coherence can be restored” (61). He suggests a new “sick role,” differing from Parsons’ (1951) definition: turning illness into a good story, to discover the narrative truth in it and to tell that truth, with the ill person as witness. Jerome Bruner’s definition of narrative truth is “altering the past in light of the present” (Frank 1995, 65). The discrepancy between historical and narrative truth is in continuity and closure, which historical truth does not always possess. Narrative truth is where historical fact borders on art, medicalized language and wonder are reclaimed, and parts of self are reconciled.

The medical encounter can be seen as an intersection of colliding narratives—that of the doctor, the patient, families and culture (again, see Fadiman’s *Spirit Catches You and You Fall Down*). To reach narrative truth is to end denial. Frank writes that narrative truth gets us closer to an “ethics of the body,” a body for other bodies, “not just in love with yourself but in love with the humanity that shares sickness as its most fundamental commonality” (64). If the mind of the storyteller changes, even as the story is being spoken, if truth is desired, truth at exactly which moment? He continues: “if truth is so hard to grab a hold of, it may instead be the case that when we narrate, a good deal of the time we also lie” (Brody 2003). It might be more authentic instead to claim that it is actually the listeners who lie by seeking narrative coherence. Brody (2003) argues that storytelling is performance and, as such, the teller is playing a role. Unless he or she is intentionally and deceptively calculating in creating a persona, the telling of the story preserves narrative truth. In other words, “there is not fiction or nonfiction, there is only narrative” (Doctorow as quoted in Morris 2001, 57).

One of my goals for my project, beyond promoting a relational concept of autonomy, is to validate my patients’ ways of knowing. Medical science accepts but one definition of truth—that which may be verified empirically via chemical testing or mechanical verification. There is truth in the poems—truth in the patients’ experience of illness and of their own bodies, and truth in their authentic relationships with their families, friends, and caregivers. By revealing this truth in narrative—this narrative truth—I seek to illuminate that there is truth other than medical test results, and this truth can be helpful in improving the medical encounter and working toward the goal of healing. If healing is achieved, then the illness ceases to be oppressive, and this fulfills the feminist goal as well.

## 8.0 CONCLUSIONS

The poetry that I “found” in my subjects’ narratives legitimizes stories and lived experiences of the patient participants, picking up where principlism leaves off and contributing to a new understanding and application of feminist bioethics. Instead of delegitimizing context and individual narratives, feminist ethical approaches seek to legitimize the experiences of all, not just those who are clearly able to possess or advocate for their own autonomy. Like medical ethics, feminist approaches to ethics see value in life stories. They allow patients and caregivers to connect in new ways, raising the standard of care and promoting possibly more beneficial treatment plans. Unlike medical ethics, feminist approaches examine the contexts and causes contributing to oppression and seek to eliminate it in all its forms. The structure of medicine (and medical education which perpetuates it generation after generation) is inherently hierarchical, and the power in the form of knowledge rests in the hands of the few. Medical ethics takes this for granted, not giving it much thought and rarely challenging it. In contrast, feminist ethics goes beyond principlism, demonstrating that the ethics are also in the details. Caring, doubtlessly, is present in medical interactions. While medical ethics tried to awkwardly and imperfectly fit it into the principle of beneficence, feminist ethical frameworks acknowledge and legitimize these aspects rather than trying to shut them out.

In her analysis of the genre of pathography, Hawkins (1999) identifies repeating themes, or myths, that appear over and over again in illness narrative. These myths become both formative illusion and profound truth (18). One pervasive myth, the battle myth, is especially pervasive, especially with regard to cancer; the idea is that the patient must fiercely fight his cancer (though it takes place in his own body) and defeat it in order to survive. In order to have a battle, there must be an enemy other, medical tools can be weapons, and physicians, allies (69). In war also, there is blame and failure and fault to be hotly avoided; medical culture has a difficult time with failure. Indeed, “our present metaphor in medicine is war and aggression; we fight disease relentlessly, often no matter the cost, and sometimes without considering very carefully how much suffering or collateral damage the battle will entail” (Coulehan, 2006b, ix). Calhoun (1988) asks,

“will we repeat the same militaristic metaphors of conquest and mastery in describing conflicts between compassion and duty which have dominated?” (695). Surely, there is gender in this battle metaphor, this connotation of war. Frank (1991) does his best to resist, asserting that, “we can’t fight cancer or tumors...illness is not a fight against an other” (89). The man who participated in this project as patient 7 also resists it, saying that he’s “not a fighter. I’ve never been in a fight in my life, I’m not a fighting-type person.” Does that doom him to death? Here, medicine’s hierarchical and gendered structure is evident. There is gender too in the “moral theories and arguments [that] are conceived of as weapons... winning might take precedence over truth” (Warren 1989, 83-84).

### *Practical Applications of Patient Listening*

If the results of my project give pause to busy physicians for even a moment, and if it is able to give voice to marginalized patients, to bring attention to a single moment in the medical encounter that is significant, and to allow the words and experiences of these patients to be expressed in a creative way that calls attention to their authentic (though non-medical) experiences, then it is worthwhile to the greater challenge of progress in bioethics. Herwaldt (2008) encourages laypeople and healthcare workers alike to read the results of her project for their own “edification and enjoyment” and to also “savor the language and the vivid descriptions, to respond both viscerally and rationally to the stories and the emotions, and to reflect on how they as practitioners can improve their relationships with patients” (9). If patients are exposed to the results, she likewise hopes that the work will encourage them to “identify which elements of their own stories are essential to their treatment and will at the same time challenge them to seek clinicians who listen attentively” (11).

It would be unrealistic and even somewhat silly to advocate that all, most, or even some physicians actually use this method and apply it to their own patients; to advocate that social workers or nurses do it would just be to perpetuate gendered stereotypes of who should be doing the caring. Instead, this project could:

- contribute to the literature: if students or physicians are able to take a few minutes to read the resulting poems, to themselves or out loud, and to discuss them with others, then they might be able to see similar experiences in their own patients, and maybe slow down to listen more closely.
- be presented during medical education or continuing medical education.
- as Herwaldt suggests, be background material for students to read when learning how to do patient histories, and learning to listen closely, as they “show how just one sentence or one word can destroy even the possibility of a therapeutic relationship” (7).
- or when students are learning about a specific disease, like cancer.
- be presented in a group setting in order to trigger discussion about ethical issues or communication or compassion or empathy, or to practice communication or listening skills, as Herwaldt found that if she “listened carefully, and deeply, I could work more efficiently and effectively and also achieve greater satisfaction for both my patients and myself” (8).
- expose others to the poems, which would be both promoting new ideas of truth in medicine and the feminist goal of eliminating oppression.
- encourage trainees to consider their patients’ experience or even try to craft poems themselves.
- Likewise, oncologists who enter into long-term relationships with patients with high stakes could try this method with the patient in order to foster a deeper relationship, more thorough communication, and a higher standard of care.

If a “narrator must keep a safe distance from the story but a lyric speaker must occupy the lyric moment as it’s happening,” then maybe, as lyric speakers, the narrators of these poems are able to get readers closer to the emotion and to the action, provoking a more powerful reaction (Manguso 2008, 166). Maybe poetic forms of narrative “commit the poet to neither closure nor openness but to some always-changing relation between the two” (Shapiro 1993, 41). These poetic narratives form a dialectic between opening and closure, and they are often in flux; they are circular, with words and themes



repeating. They resist ending or concluding. According to narrative ethics, ethical principles and theories are derived from stories, which then translate into lived experience in a circular way; poetry is likewise circular, often without a clear beginning or end. Narrative is essential for ethical medical practice: indeed, narrative is essential in revealing our own deepest values, some of which only emerge when viewed through a specific life story (Charon and Montello 2002). Morris (2001) writes that “narrative does not necessarily tell us who is right or wrong, it actively undermines the false confidence... that ethical dilemmas necessarily call or accommodate a singular right action” (64). Likewise, Sleight (2006) finds that, instead of taking sides, poetry is simultaneously responsive to all sides at once.

Like Herwaldt, this experience and these “narratives taught me to welcome patients’ stories” (8). Coulehan (2006b) muses that sometimes it seems that poetry can break through an impenetrable barrier. Rather than solely in overarching theory, medical ethics exists in the details and contexts of the lives and experiences of patients. Ethical conclusions might change with more understanding of context. Frank (1995) references the “ethical ideal of existing for the other,” writing that “by telling stories, ethical choices are made” (52). My original contribution to the field of bioethics is embodied in a creative way of expressing patient experience. I amplified the voices of patients not previously heard in a unique way, validating their narrative ways of knowing as different but complementary to physician perspectives. These perspectives are also truth, though different from empirical truth, and they can be at least as valuable in the shared interest of healing. The patients who participated in my study are empowered beyond this validation—by giving them some control over their own narratives and experiences of illness, by giving them some choice over how to frame their own stories, and by trusting these stories as true and authentic, regardless of their verifiability. In my poems is evidence of how deeply embedded my subjects are in their social and familial networks, and how no medical choice is made in a vacuum. They are not fiercely independent and atomistic agents, particularly in illness, and to base their autonomy in such an understanding would be inaccurate. Their narratives provide evidence for a more robust, relational view of autonomy. My patient-subjects are oppressed by their status of not being trusted as truth-tellers in contrast with medical ways of knowing. They are

oppressed by illness. My project fulfills the feminist dictum of working to eliminate oppression, in whatever form it may be—just as there are different definitions of oppression, there are different definitions of autonomy and truth, and I have sought to illuminate them.

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## CURRICULUM VITAE

**Jill Lauren Kauffman**

### EDUCATION

- **2009.** Master of Arts in Philosophy—Biomedical Ethics, Indiana University, Indianapolis, Indiana. Thesis title: “Poetry ‘Found’ in Illness Narrative: A Feminist Approach to Patients’ Ways of Knowing and the Concept of Relational Autonomy.” Chair: Peg Brand, PhD.
- **2002.** Bachelor of Arts in English Language and Literature, University of Maryland at College Park.
- **2001.** Semester in British History, Society, and Politics. Exeter College, Oxford University, England.
- **1997.** Multi-Environment Wilderness Leadership Semester, Pacific Crest Outward Bound School. Rock Climbing, Kayaking, Mountaineering, Wilderness Medicine. California and Mexico.

### HONORS AND AWARDS

- Winner, 2009 Medical Humanities-Health Studies Student Essay Award, Indiana University-Purdue University-Indianapolis.
- Graduated with Phi Beta Kappa and Cum Laude honors.

### PRESENTATIONS

- *The Vigil of Breathing and Decay: The Prose Poetics of Illness, Body, and Ethics.* Paper presented at “Imaging America,” Great Lakes American Studies Conference, University of Notre Dame, March 19-21, 2009.
- *Physician-Authored Pathography as an Answer to Issues of Empathy Loss Resulting from Traditional Medical Socialization.* Paper presented at “Cancer Stories: The Impact of Narrative on a Modern Malady.” November 6-8, 2008. Indianapolis, Indiana.

### RESEARCH INTERESTS

- Narrative medicine, particularly narrative oncology
- Literature and medicine and medical humanities
- Clinical medical ethics
- Feminist ethics
- Environmental ethics
- Emergency, wilderness, travel, and expedition medicine